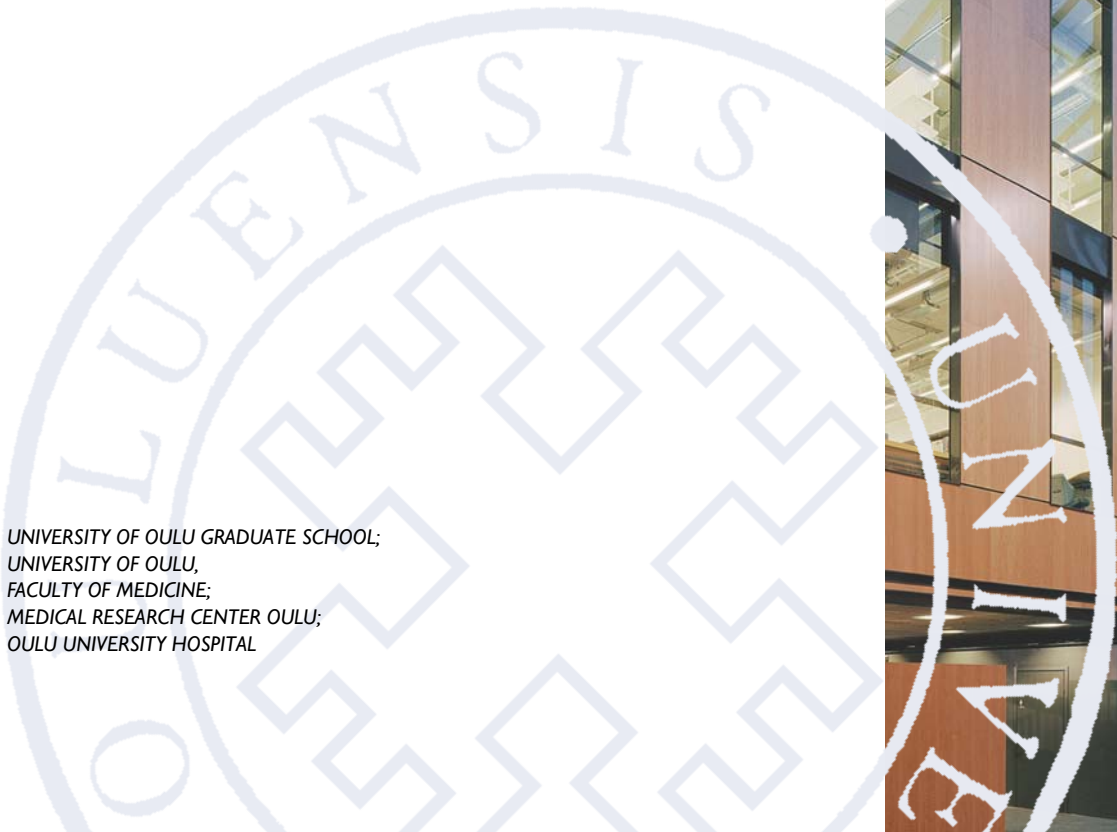


*Hanna-Mari Pesonen*

# MANAGING LIFE WITH A MEMORY DISORDER

THE MUTUAL PROCESSES OF THOSE WITH  
MEMORY DISORDERS AND THEIR FAMILY  
CAREGIVERS FOLLOWING A DIAGNOSIS

UNIVERSITY OF OULU GRADUATE SCHOOL;  
UNIVERSITY OF OULU,  
FACULTY OF MEDICINE;  
MEDICAL RESEARCH CENTER OULU;  
OULU UNIVERSITY HOSPITAL





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DISORDER**

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and their family caregivers following a diagnosis

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***Abstract***

The prevalence of memory disorders is increasing worldwide due to an aging population. The condition affects not only those with the disorder, but also their families and the wider social network. Establishing services that meet the needs of patients and their families is a topical issue and requires knowledge produced from service user viewpoints. However there remains limited knowledge of how families manage their lives when there is a memory disorder.

This study produces a substantive theory that describes the processes of managing life after disclosure of a progressive memory disorder from the viewpoint of individuals with that diagnosis and their family caregivers. A qualitative longitudinal research design informed by grounded theory methodology was undertaken. Research data were gathered for 2006–2009 using in-depth interviews (n=40) from those with the memory disorder (n=8) and their family caregivers (n=8). The data were analyzed using a constant comparative analysis.

A core category ‘Accepting memory disorder as part of family life’ with related categories and subcategories was formulated from the gathered data. Family illness trajectory begins when patients or close relatives recognize the symptoms. Diagnosis of memory disorder is a turning point in that trajectory. It changes the course of lives for both individuals and their whole family and leads families to seek a new equilibrium. Altering life challenges people with the diagnosis and their family caregivers to restructure their roles and identities. Adjusting to altering self and adapting to the new role of caregiver are intertwined processes. Families strive to manage these changes by acknowledging available qualities and resources, seeking meaningful social support and living for today. Managing life with a memory disorder produces mutual processes in families that contain both positive and negative factors. Accepting memory disorder as part of family life represents a hope-fostering adjustment.

The findings confirm and supplement the knowledge base in nursing science of family experiences and the means families use for managing life after diagnosis of a progressive memory disorder. These findings can be well utilized by professionals working with patients and their families who are living with newly diagnosed memory disorder while also advancing nursing education.

*Keywords:* family caregiver, family health, grounded theory –methodology, life change events, life management, memory disorder, person with memory disorder



# **Pesonen, Hanna-Mari, Elämä etenevän muistisairauden kanssa. Muistisairaiden ja omaishoitajien vastavuoroiset elämänhallinnan prosessit diagnoosin varmistumisen jälkeen**

Oulun yliopiston tutkijakoulu; Oulun yliopisto, Lääketieteellinen tiedekunta; Medical Research Center Oulu; Oulun yliopistollinen sairaala

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## ***Tiivistelmä***

Väestön ikääntymisen vuoksi muistisairauksien esiintyvyys on kasvussa koko maailmassa. Etenevä muistisairaus vaikuttaa sekä sairastuneiden että perheiden elämään, ja heidän tarpeisiinsa vastaavien palvelujen kehittäminen on ajankohtaista. Perheiden selviytymistä koskevaa tutkimustietoa palvelujen kehittämiseksi on kuitenkin rajallisesti.

Tutkimuksen tarkoituksena oli kehittää aineistolähtöinen teoria, joka kuvaa muistisairaiden ja omaishoitajien elämänhallinnan prosesseja muistisairausdiagnoosin varmistumisen jälkeen. Tutkimus oli laadullinen pitkäaikaistutkimus, jossa aineisto kerättiin vuosina 2006–2009 syvähaastattelulla (n=40) sekä sairastuneita (n=8) että heidän omaisiaan (n=8). Aineisto analysoitiin grounded theory -metodologian jatkuvan vertailun analyysimenetelmällä.

Tutkimuksessa tuotetun aineistolähtöisen teorian ydinkategoriaksi muodostui 'Muistisairauden hyväksyminen osaksi perheen elämää'. Ydinkategoriaan olivat yhteydessä pää- ja alakategoriat, jotka kuvasivat vastavuoroisia elämänhallinnan prosesseja perheessä. Perheiden kehityskulku muistisairaudesta käynnistyi ennen diagnoosin varmistumista, kun sairastunut itse tai hänen läheisensä kiinnittivät huomiota oireisiin. Muistisairausdiagnoosi oli käännekohta, joka muutti perheiden elämänkulun suuntaa ja johti etsimään uutta tasapainoa elämässä. Muuttuva elämäntilanne haastoi sairastuneet ja heidän omaisensa rakentamaan uudelleen käsitystä itsestään ja sosiaalisista rooleistaan. Sairastuneiden kokemuksena tämä tarkoitti sopeutumista muuttuvaan itseen ja omaisten kokemuksena mukautumista uuteen omaishoitajan rooliin. Nämä kehityshaasteet kytkeytyivät toisiinsa. Perheet pyrkivät selviytymään muuttuvassa elämäntilanteessaan huomioimalla käytettävissä olevat voimavarat, hyödyntämällä merkityksellistä sosiaalista tukea ja tavoittelemalla elämää tässä ja nyt. Muistisairaiden ja omaishoitajien vastavuoroiset elämänhallinnan prosessit sisälsivät sekä myönteisiä että kielteisiä tekijöitä. Muistisairaudesta hyväksyminen osaksi perheen elämää merkitsi toivoa vahvistavaa sopeutumista.

Tutkimustulokset täydentävät hoitotieteen tietoperustaa perheiden kokemuksista ja elämänhallinnan keinoista muistisairausdiagnoosin varmistumisen jälkeen. Tutkimustuloksia voidaan hyödyntää sekä käytännön hoitotyössä tuettaessa muistisairaita ja heidän perheitään diagnoosin jälkeen että hoitotyön koulutuksessa.

*Asiasanat:* elämänhallinta, elämänmuutostapahtumat, grounded theory –metodologia, muistisairas henkilö, muistisairaus, omaishoitaja, perheen terveys





*To families who are living  
with a memory disorder*



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*"A person is a person through other people."  
An African saying*

Oulu, March 2015

Hanna Pesonen



## List of original articles

This thesis is based on the following publications, which are referred throughout the text by their Roman numerals:

- I Pesonen HM, Remes AM, Isola A (2011) Ethical aspects of researching subjective experiences in early-stage dementia. *Nursing Ethics* 18(5): 651–661.
- II Pesonen HM, Remes AM, Isola A (2013) Diagnosis of dementia as a turning point among Finnish families: A qualitative study. *Nursing and Health Sciences* 15(4): 489–496.
- III Pesonen HM, Remes AM, Isola A (2014) Managing life-altering situations: A qualitative longitudinal study of the experiences of people with memory disorders and their family caregivers. *Journal of Nursing Education and Practice* 4(10): 60–73.





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# 1 Introduction

As a progressive neurodegenerative condition, memory disorder influences not only to a patient's life, but also his or her social network (Alzheimer's Disease International 2009, Daly *et al.* 2013, Podgorski & King 2009, World Health Organization 2012). The prevalence of memory disorders is increasing due to improvements in life expectancy and aging of the population. It is estimated that in 2010, there were 35.6 million people worldwide living with memory disorder, and these numbers are expected to almost double every 20 years to 65.7 million in 2030 and 115.4 million by 2050. In Europe alone, there are currently more than seven million people living with memory disorder. (Prince *et al.* 2013, World Health Organization 2012). In Finland the population is getting older faster than it is in several other countries due to the baby boomers and general prolongation of lifespan (Ministry of Social Affairs and Health 2011). Annually, approximately 13 000 people are affected by memory disorder in Finland. Over 95 000 patients have been diagnosed with at least a moderate memory disorder, and approximately 30 000–35 000 diagnosed with a mild memory disorder. It is estimated that by 2020 approximately 130 000 individuals will be living with at least a moderate level of memory disorder. (Ministry of Social Affairs and Health 2013a). Although age is a risk factor, memory disorder also touches younger people, who along with their families face unique challenges in their lives (Ducharme *et al.* 2013, Harris 2004, Harris & Keady 2004, Harris & Keady 2009, Rose *et al.* 2010, Svanberg *et al.* 2011, van Vliet *et al.* 2010). In Finland, there are approximately 5 000–7 000 individuals younger than 65 years living with this disorder (Ministry of Social Affairs and Health 2013a).

Currently there is a strong concern globally and in both Europe and in Finland about establishing social and health care services that support early diagnosis, are rehabilitative, meet the needs of patients with memory disorders and their family caregivers, and fully support their quality of life (Act on Care Services for the Elderly 980/2012, Alzheimer's Disease International 2009, Commission of the European Communities 2009, Council of the European Union 2008, European Parliament 2011, Ministry of Social Affairs and Health 2013a, Ministry of Social Affairs and Health 2014, OECD 2013, Suhonen *et al.* 2008a, World Health Organization 2012). Several European countries either have or are preparing national action plans aimed at improving the quality of life of those affected by memory disorder (Alzheimer Europe 2014), including Finland (Ministry of Social Affairs and Health 2013a). The objective for this care and

rehabilitation is that services be seamless and tailored to the individual needs of both the patient and the family. Rehabilitation optimizes a patient's functional ability, slows down the rate of decline, maintains the quality of life and prepares the patient to continue living at home. (Ministry of Social Affairs and Health 2013a, Ministry of Social Affairs and Health 2013b, Suhonen *et al.* 2008a). Families and others in the immediate network of those with a memory diagnosis have an important role in planning and carrying out informal care and rehabilitation that supports the patient (Innes 2009, Ministry of Social Affairs and Health 2013b, World Health Organization 2012).

Strengthening the client and family's position in social and health care, securing their opportunities to take part in both the planning and conducting of care, and providing individual care are the main focuses of action in Finland's social and health care policy (Ministry of Social Affairs and Health 2006, Ministry of Social Affairs and Health 2013b). Although Finnish nurses in general seem to have a positive perception toward providing individualized care for the patients (Suhonen *et al.* 2010), the needs of their patients are not always met (Suhonen *et al.* 2005a, Suhonen *et al.* 2009). Understanding the service user viewpoint is thus essential, and it is necessary to include them in the research and highlight their subjective experiences when generating the knowledge base in nursing (Gagliardi *et al.* 2008, Porter *et al.* 2011). The development of services that fully meet the needs and enhance the quality of life of those with memory disorders and their family caregivers requires knowledge obtained from the patients' and families' viewpoints (Cheston *et al.* 2000, Gilmour & Brannelly 2010, Goldsmith 2002, Innes 2009, Wilkinson 2002).

Research in social and health sciences began to focus on the subjective experiences of people with memory disorder in the 1990's and this interest has grown considerably since then (Innes 2009). Most of the studies have focused on the subjective experiences of living with memory disorder and been cross-sectional studies; therefore, more longitudinal studies are needed (Steeman *et al.* 2006). Previous studies concerning either the experiences of those with the diagnosis or informal family caregivers have mainly focused on the challenges of living with memory disorder: The impact of the diagnosis on patient selfhood and identity, and coping strategies among patients (Clare 2003, Gilmour & Huntington 2005, Harman & Clare 2006, Mok *et al.* 2007, Pearce *et al.* 2002, Preston *et al.* 2007), and the informal caregivers' experiences on changes in relationships, stress, their burden, and coping strategies (Etters *et al.* 2008, Innes

2009, Kim *et al.* 2012, Papastavrou *et al.* 2007, Papastavrou *et al.* 2011, Quinn *et al.* 2008, Schoenmakers *et al.* 2010, Stolt *et al.* 2014).

The previous research has mainly brought forth certain negative influences, such as the losses and strain, while the more positive aspects, such as remaining hopeful and living an enriched life with memory disorder, have only recently challenged that negative orientation (Beard *et al.* 2009, Wolverson *et al.* 2010). Further, previous research has paid scarce attention to family dynamics and interpersonal processes when families do learn to live with progressive memory disorder. Intrapersonal processes have usually been of interest, and the need to understand the interpersonal and dyadic processes involved in giving and receiving care has been highlighted (Braun *et al.* 2009, Nolan *et al.* 2004).

The purpose of this study then is to produce a substantive theory that describes the mutual processes of managing life after the disclosure of a diagnosis of progressive memory disorder by those with the diagnosis and their family caregivers. There is a need in nursing practice and nursing education for more research-based knowledge that brings forward the possibilities to establish family-centered care and rehabilitation for both the individuals and the families living with memory disorder. Experiential knowledge is necessary when developing services that will support individuals and families and help them manage their lives despite the disorder and still maintain the best quality of life.



## 2 Review of the literature

Dementia is a syndrome of cognitive decline that impairs people's independent functioning in daily life, work and social relationships. The symptoms can be progressive, but they can also be a stable memory disorder, for example, due to brain injury, or they can be reversible with treatment. Progressive memory disorder can be caused by different neurodegenerative diseases. The most common underlying conditions are Alzheimer's disease (70%), vascular dementia due to cerebrovascular pathology (15–20%), and pathology related to Lewy bodies (10–15%). Impairment of memory is a general symptom of progressive memory disorder, but a decline of other higher brain functions is related. Depending on the disease, the symptoms are related to speech and language impairment and difficulties in observing and understanding visual perception, undertaking planning, maintaining concentration, and doing problem-solving. Furthermore there can be changes in that person's mood and behavior. Symptoms also can affect an individual's ability to carry out previously familiar activities and hinder his or her independent functioning and social relationships. (Bouchard 2007, Memory Disorders: Current Care Guidelines 2010).

Beside those affected with the actual memory disorder, the condition inevitably affects the families and the wider social network. Living with memory disorder affects family dynamics (Podgorski & King 2009) and alters families' experiences and interactions with other people, organizations, and society (Daly *et al.* 2013). Families have a vital role to play in providing informal care for their loved ones with a memory disorder (Podgorski & King 2009, Schulz & Martire 2004, World Health Organization 2012). Family caregiving is a long-term evolving process that passes through different phases due to the progression of the condition (World Health Organization 2012).

This review of the literature consists of three parts. First, living with memory disorder from the patient's viewpoint is described. Secondly, this theme is then viewed from the family caregiver perspective, and then a summary of the results and characteristics of previous studies is given. According to Glaser & Strauss (2008), it is possible to review the relevant existing literature in the early phases of a grounded theory study if that literature enhances sensitivity and advances the full research process. The researcher needs to be conscious of the risk in that the literature review could conceivably hinder the substantive theory from being inductively grounded in the data (Cutcliffe 2000, McGhee *et al.* 2007). In the current study, a preliminary use of literature helped identify the gaps in previous

knowledge and provided a clear framework for the interviews. Engaging the literature in a deeper way took place when writing the original articles to confirm the findings. A more thorough literature review in the substantive area was conducted while writing the summary after the completed theory was formulated to combine the empirical findings with already existing knowledge.

## 2.1 Living with memory disorder from the patient's perspective

In order to produce an overview of previous qualitative studies of living with memory disorder from the view of those with the actual diagnosis, a literature search was performed using the Ovid Medline, Cinahl and PsycINFO databases and the following search terms: Dementia OR dement\* OR Alzheimer disease OR memory disorders OR memory disease AND subjective experience\* OR experience\* OR illness experience\* AND qualitative research. These searches were limited to the English language and to peer-reviewed publications from 2000 to May 2014. Inclusion criteria for the selected studies were: 1) they were scientific empirical studies or systematic literature reviews; 2) search terms were found in the title and / or in the abstract for the most part; and 3) each study focused on experiences of home-dwelling patients with memory disorder during the pre-diagnostic and / or diagnostic and / or post-diagnostic phase. In order to confine the literature and better equate the sample with the purpose of the current study, studies were excluded if they focused either on mild cognitive impairment or on the later stages of memory disorder, or on patient experiences with health care services, or solely on the experiences of family caregivers, or if the studies were intervention ones. The studies that met these criteria are presented in Table 1. Altogether, 34 studies were selected after duplicates (n=9) were removed. In addition, manually selected studies (n=13) as well as two Finnish doctoral theses were included in this literature review.

**Table 1. Literature search on those living with memory disorder from a patient perspective.**

Database	Search results (n)	Selected studies (n) <sup>1</sup>
Ovid Medline	132	10
Cinahl	35	3
PsycINFO	437	30

<sup>1</sup> Includes duplicates



### **2.1.1 The pre-diagnostic path of patients**

Living with memory disorder is an individualized and complex process that is formed in a sociocultural context (Bunn *et al.* 2012, Hulko 2009, O'Connor *et al.* 2010). It consists of different stages (Heimonen 2005, Keady *et al.* 2007, Steeman *et al.* 2006, Werezak & Stewart 2002). The transitional process starts before a diagnosis is confirmed when the person becomes aware of diverse early symptoms of cognitive decline (Heimonen 2005, Johannessen & Möller 2013, Koehn *et al.* 2012, Leung *et al.* 2011, Parsons-Suhl *et al.* 2008, Steeman *et al.* 2006, Werezak & Stewart 2002).

Seeking help is a long emotional journey before the diagnosis is fully confirmed (Samsi *et al.* 2014). Experiencing the stigma, normalizing or minimizing the symptoms, or lacking an awareness of the symptoms of a progressive memory disorder may actually be barriers to early diagnosis (Bunn *et al.* 2012, Heimonen 2005, Werezak & Stewart 2002). Especially, elderly people may see forgetfulness as an expected part of aging, and that belief may delay the process of seeking professional help for their memory problems (Koehn *et al.* 2012, Leung *et al.* 2011). Acknowledging the severity of serious cognitive health problems usually will lead people to seek help (Leung *et al.* 2011), but that decision may often need a trigger event and support from close relatives before the patient decides to proceed with a medical examination (Bunn *et al.* 2012).

### **2.1.2 Impact of the diagnosis on patient**

Diagnosis of a memory disorder evokes a wide range of negative feelings: Shock, denial, anger, fear, worry, depression, anxiety, and uncertainty (Bunn *et al.* 2012, Clare *et al.* 2008, Derksen *et al.* 2006, Harris & Keady 2009, Heimonen 2005, MacQuarrie 2005, Parsons-Suhl *et al.* 2008, Samsi *et al.* 2014, Steeman *et al.* 2006, Vernooij-Dassen *et al.* 2006, von Kutzleben *et al.* 2013, Werezak & Stewart 2002), thus affecting the well-being of the person just diagnosed. Confirmation of such a diagnosis is a significant turning point that leads to a process of coming to terms with a progressive condition, adjusting to its gradual changes, managing an altering life situation and finding a new balance in one's life (Beard 2004, Clare *et al.* 2008, Gilmour & Huntington 2005, Heimonen 2005, Keady *et al.* 2007, Langdon *et al.* 2007, Steeman *et al.* 2006, Vernooij-Dassen *et al.* 2006, Werezak & Stewart 2002).

A diagnosis can actually be a confirmation of suspicions (Derksen *et al.* 2006, Heimonen 2005, Vernooij-Dassen *et al.* 2006), or even be experienced as a relief of such suspicions (Derksen *et al.* 2006, Heimonen 2005), and actually empower that person to consider the future (Samsi *et al.* 2014). Previous research has shown that there are positive aspects to telling other people about a diagnosis (Beard 2004, Gilmour & Huntington 2005, Heimonen 2005, Vernooij-Dassen *et al.* 2006). People feel comfortable about sharing their diagnosis with their family members or others in the immediate network, but still want to be in control over how widely they confirm their situation due to their fear of other people's reactions (Heimonen 2005, Langdon *et al.* 2007, Werezak & Stewart 2002) or simply because they want to protect others from the information they now have (Heimonen 2005).

### **2.1.3 Memory disorder impacts the patient sense of self**

Previous research has shown how memory disorder threatens an individual's sense of self and identity as being an autonomous and competent person (Beard & Fox 2008, Clare *et al.* 2008, Harman & Clare 2006, Harris & Keady 2004, Harris 2004, Preston *et al.* 2007, Steeman *et al.* 2006, Steeman *et al.* 2007, Virkola 2014). However, they still do have a need to be valued and accepted (Mazaheri *et al.* 2013, Sørensen *et al.* 2008b, Steeman *et al.* 2007, Steeman *et al.* 2013), be understood by others and taken seriously (O'Connor *et al.* 2010, von Kutzleben *et al.* 2013), be treated as normally as possible (Beard *et al.* 2009, Beattie *et al.* 2004, Langdon *et al.* 2007) and be able to maintain their dignity (Johannessen & Möller 2013). Although declining abilities will provoke feelings of incompetence, it is still important that a person can maintain a sense of agency and involvement in life (Virkola 2014). People with early-stage memory disorder can find ways to manage and preserve their positive identity with both resilience and resourcefulness (MacRae 2010). Remaining independent and competent enough and not seeing oneself as a burden, but instead as being helpful to others (MacRae 2010, Mok *et al.* 2007, Samsi *et al.* 2014, Steeman *et al.* 2007, Steeman *et al.* 2013, Vernooij-Dassen *et al.* 2006) are meaningful goals for people with a memory disorder and lets them prevent their feelings from making them become a victim of the disease (O'Connor *et al.* 2010).

Memory disorders threaten each patient's valued familiar elements of life (Lawrence *et al.* 2011, Parsons-Suhl *et al.* 2008), affects their future plans and possibilities (Clare *et al.* 2008), and leads to feelings of confusion and uncertainty

(Svanström & Dahlberg 2004). To confront these challenges, these people need to develop and use various emotional, practical, and social management strategies to cope with their now altering situation (Beard & Fox 2008, Beard 2004, Beard *et al.* 2009, Bunn *et al.* 2012, Heimonen 2005, MacQuarrie 2005, Mok *et al.* 2007, Parsons-Suhl *et al.* 2008, Preston *et al.* 2007, Sørensen *et al.* 2008b, Virkola 2014). These strategies can be either self-protective, aiming toward maintaining normality and continuity in life, or integrative strategies where people openly confront the difficulties and adjust to the disorder (Clare 2002, Clare 2003, Steeman *et al.* 2006). Managing an altering self is a cyclical process of maintaining the prior sense of self while reconstructing a new sense of self that has the disorder (Bunn *et al.* 2012, Pearce *et al.* 2002).

#### **2.1.4 Memory disorder impacts patient social roles**

Patient activity and independent performance in everyday life is naturally affected by the disorder and the condition also lead to a need for assistance from other people (Beard & Fox 2008, Frazer *et al.* 2012, Gilmour & Huntington 2005, Phinney *et al.* 2013, Svanström & Dahlberg 2004, Vikström *et al.* 2008). This dependency on others influences their roles, responsibilities and relationships within the family (Bunn *et al.* 2012, Derksen *et al.* 2006, Harris 2004, Langdon *et al.* 2007, Mok *et al.* 2007, Phinney *et al.* 2013, Vernooij-Dassen *et al.* 2006, Vikström *et al.* 2008) but also the wider social network (Bunn *et al.* 2012, Gilmour & Huntington 2005, Langdon *et al.* 2007). Being dependent on others' help may cause contradictory experiences and feelings of being a burden to others (Clare 2003, Derksen *et al.* 2006, Mazaheri *et al.* 2013, Mok *et al.* 2007, Steeman *et al.* 2013, Vernooij-Dassen *et al.* 2006, Ward-Griffin *et al.* 2006, Werezak & Stewart 2002). Therefore people will actively try to maintain their independence and control over their own lives (Gilmour & Huntington 2005).

Memory disorder changes the way other people treat the person who is diagnosed (Harman & Clare 2006). People living with memory disorder find themselves now different than others (Mazaheri *et al.* 2013). They are aware of other people's responses (Langdon *et al.* 2007, Mok *et al.* 2007) and experience the stigma associated with having their disorder (Clare *et al.* 2008, Virkola 2014, von Kutzleben *et al.* 2013). However, being socially connected to others and gaining meaningful social support from close relatives and their wider network is significant (Derksen *et al.* 2006, Frazer *et al.* 2012, Heimonen 2005, Phinney *et al.* 2013, Pison-Young *et al.* 2012, Preston *et al.* 2007, Steeman *et al.* 2006,

Wolverson *et al.* 2010) to promote successful coping with the disorder. A positive sense of self can be sustained if a diagnosed person's social experience is positive, supportive, and encouraging (MacRae 2010).

### **2.1.5 The influence of age on life of the patient**

According to earlier research, people with a memory disorder face multiple psychological, social, and functional losses in living (Clare *et al.* 2008, Frazer *et al.* 2012, Mok *et al.* 2007, Phinney *et al.* 2013, Robinson *et al.* 2011). It is notable as well that there are differences in the challenges that are faced by those living with early-onset versus late-onset memory disorder. Although there are similar experiences, regardless of age, younger people face unique experiences with quite different challenges, as they have additional stressors because of their age, social roles and family situations. (Beattie *et al.* 2004, Harris & Keady 2004, Harris 2004, Harris & Keady 2009, O'Connor *et al.* 2010, Rose *et al.* 2010).

Becoming dependent on others' assistance can be especially difficult to accept for younger patients (Harris & Keady 2004, Harris 2004). Losing a career and gradually giving up meaningful activities are particular challenges for people facing an early-onset memory disorder (Harris & Keady 2004, Harris 2004, Harris & Keady 2009, Heimonen 2005). Giving up a job can also bring financial hardships (Harris & Keady 2004, Harris 2004, Rose *et al.* 2010). Different losses will affect a person's identity as an individual, employee, member of the family, and a sexual and social being (Harris & Keady 2009). Further, younger people with an early-onset memory disorder have stronger feelings of being isolated and marginalized because of their age than older people with a memory disorder will have (Harris & Keady 2004, Harris 2004, Rose *et al.* 2010).

### **2.1.6 Factors that promote patient coping**

Focusing on the present is a counterbalance to the fear of illness progression and the unknown future (Beard *et al.* 2009, Bunn *et al.* 2012, de Witt *et al.* 2010, MacRae 2010). Maintaining a sense of hope is related to living just one day at a time with current functioning (Heimonen 2005, Wolverson *et al.* 2010) and adjusting to the altering situation by finding a balance between the negative and positive aspects of the disorder (Clare 2002). Medication can promote an individual's hope to hold back time and feel optimistic about the future (Clare 2002, Clare 2003, de Witt *et al.* 2010, Pearce *et al.* 2002). People try to find

positive aspects in their lives by focusing on their remaining capacities and minimizing the problems (Steeman *et al.* 2007), indeed maintaining a sense of continuity in their lives (Beard *et al.* 2009) and focusing on the good things and keeping a strong fighting spirit (Clare 2002, Clare 2003, Heimonen 2005). Humor is commonly used as a strategy to confront the changes and adapt to the altering situation (Beard & Fox 2008, Bunn *et al.* 2012, Heimonen 2005, Hulko 2009, Keady *et al.* 2007, Langdon *et al.* 2007, MacRae 2010, Mazaheri *et al.* 2013, Parsons-Suhl *et al.* 2008, Phinney *et al.* 2013).

Memory disorder is not always experienced completely as a negative event. People can deal with the disorder with a positive attitude and view their condition more as a challenge than a threat (von Kutzleben *et al.* 2013). If a person has experienced other disadvantages in life prior to the diagnosis, then he or she may tolerate the effects of the disorder and have more resilience when dealing with their altering life situation (Hulko 2009). Despite the progressive nature of the memory disorder and its negative consequences, however, the situation can be experienced as a manageable disability (Beard *et al.* 2009).

## **2.2 The family caregiver's perspective of living with a memory disorder**

To create an overview of previous qualitative studies of family caregivers' experiences when dealing with a memory disorder, a literature search was performed using the Ovid Medline, Cinahl and PsycINFO databases and the following search terms: Dementia OR dement\* OR Alzheimer disease OR memory disorders OR memory disease AND family caregiv\* OR caregivers OR family AND subjective experience\* OR experience\* AND qualitative research. The searches were limited to the English language and to peer-reviewed publications from 2000 to June 2014. Inclusion criteria for the selected studies were: 1) they were scientific empirical studies or systematic literature reviews; 2) search terms were found in the title and / or in the abstract for the most part; and 3) the study was focused on family caregivers' experiences when caring for a home-dwelling person with a memory disorder during the pre-diagnostic and /or diagnostic and / or post-diagnostic phase. To confine the literature to equate the sample with the purpose of the present study, studies were excluded if they focused either on mild cognitive impairment or on the later stages of memory disorder or solely on a specific ethnic group and the disorders' cultural meanings, or the family caregivers' experiences of health care services, use of technology or

clinical trials, or if the studies were intervention ones. The number of studies meeting these criteria are presented in Table 2. Altogether, 64 studies that met the inclusion criteria were selected after the duplicates (n=23) were removed.

**Table 2. Literature search on those living with a memory disorder from the family caregiver perspective**

Database	Results (n)	Selected studies (n) <sup>1</sup>
Ovid Medline	92	24
Cinahl	15	7
PsycINFO	297	56

<sup>1</sup> Includes duplicates

To acquire a more comprehensive understanding of the family caregiver experience, a supplementary literature search of studies using questionnaires was performed using the Ovid Medline and Cinahl databases and the following search terms: Dementia OR Alzheimer disease OR memory disorders AND Questionnaires AND Adaptation, psychological AND caregivers. These searches were limited to studies from 2010 onwards in the English language. Studies were included if they focused on family caregivers of a home-dwelling person with recently diagnosed memory disorder or disorders in their early stages, at least partially. Five studies were selected in this way. In addition, five manually selected studies and one Finnish doctoral thesis were included in this particular literature review.

### **2.2.1 The pre-diagnostic path of family caregivers**

From the family caregivers' point of view, living with a close one's memory disorder is a process that contains different stages. Like the patients, family caregivers too become aware of the symptoms and notice different changes in a close family member's behavior and functioning before the diagnosis is actually confirmed (Adams 2006, Bunn *et al.* 2012, Chrisp *et al.* 2012, Ducharme *et al.* 2013, Galvin *et al.* 2005, Heimonen 2005, Leung *et al.* 2011, Morgan *et al.* 2014, Samsi *et al.* 2014, Välimäki *et al.* 2012). During the pre-diagnostic phase, those in the immediate family will experience distress and frustration, as they do not know the reason for their close one's behavior (Morgan *et al.* 2014).

As for the patients, family caregivers' experiences also indicate that there is often a specific triggering incident or growing changes that lead these families to

seek help from health services (Adams 2006, Bunn *et al.* 2012, Chrisp *et al.* 2012, Heimonen 2005, Leung *et al.* 2011, Morgan *et al.* 2014). It is notable that close relatives often will have an active role in encouraging their close one to seek help (Chrisp *et al.* 2012, Heimonen 2005, Leung *et al.* 2011, McCleary *et al.* 2013, Morgan *et al.* 2014, Samsi *et al.* 2014, Välimäki *et al.* 2012). However, seeking help for a close one is not necessarily straightforward, and there may be some delay in contacting health care professionals due to uncertainty, disagreement, or even denial within the family about the nature of the symptoms, trying to normalize the symptoms, or even being unaware of the underlying cause of the changes seen in their close one's behavior (Chrisp *et al.* 2012, Daly *et al.* 2013, Hughes *et al.* 2009, Leung *et al.* 2011, McCleary *et al.* 2013). The family's entry into the care trajectory is influenced by several factors that relate to the individual's and the family's past experiences, their present situation, the family system and closeness, and organizational issues (Carpentier *et al.* 2010, Hughes *et al.* 2009).

## **2.2.2 Impact of the diagnosis on family caregivers**

Receiving a diagnosis is also a turning point for the close relatives (Bakker *et al.* 2010). A confirmation of such a diagnosis is experienced as a shock, especially if it's not suspected and because it undermines their views of the future (Derksen *et al.* 2006, Ducharme *et al.* 2013, Heimonen 2005, Potgieter & Heyns 2006, Pretorius *et al.* 2009, Prorok *et al.* 2013, Samsi *et al.* 2014). For adult children, a parent's diagnosis can cause additional uncertainties, such as fear of a possible genetic predisposition (Stone & Jones 2009). However, similarly as for those with the actual diagnosis, family caregivers can experience the diagnosis as a sort of relief (Derksen *et al.* 2006, Ducharme *et al.* 2013, Heimonen 2005, Prorok *et al.* 2013, Välimäki *et al.* 2012, Williams *et al.* 2014). Knowing and understanding the reason for a close one's behavior can help family caregivers re-orientate and adjust to the changing situation and move forward positively in life (Bakker *et al.* 2010, Morgan *et al.* 2014, Potgieter & Heyns 2006, Stokes *et al.* 2014, Välimäki *et al.* 2012).

Becoming a family caregiver is a dynamic process where the family caregiver faces conflicts due to the altering situation and simultaneously trying to manage their own life while yet adjusting to their new position in a care-giving relationship (Che *et al.* 2006, Lin *et al.* 2012). For the family caregiver, living with a close one's memory disorder is a trajectory aimed at maintaining continuity

and facing loss (Gillies 2012). As the diagnosed person's activity gradually decreases and social engagement diminishes, the family caregiver becomes a linchpin for promoting independence, encouraging participation and involvement in activities, and protecting the person with the disorder (Adams 2006, Bunn *et al.* 2012, Chung *et al.* 2008, Kindell *et al.* 2014, Phinney *et al.* 2013, Samsi *et al.* 2014, Sanders & Power 2009, Taşcı *et al.* 2012, Vikström *et al.* 2008). The caregiver will start to take on more responsibility of everyday life decision-making (Bakker *et al.* 2010, Heimonen 2005, Quinn *et al.* 2008, Samsi & Manthorpe 2013), as they simultaneously aim to support the identity, self-esteem and dignity of the person who has been diagnosed (Daly *et al.* 2013, Heimonen 2005, Sanders & Power 2009), take care of their own and the whole family's wellbeing and social relationships, and deal with their own personal duties and obligations (Daly *et al.* 2013, Heimonen 2005).

### **2.2.3 The meaning of caregiving**

Caregiving is a unique experience, and it has diverse meanings for the family caregiver. The marital commitment can give meaning to the caregiving (Eriksson *et al.* 2013, Lee & Smith 2012, Sanders & Power 2009, Shim *et al.* 2013), although caregiving can also be perceived as an obligation expected of others and a personal responsibility or even a necessity due to the lack of any alternative support (Che *et al.* 2006, Lee & Smith 2012, Williams *et al.* 2014). The previous relationship between the caregiver and the care receiver can also influence both the ability and the willingness to care (Williams *et al.* 2014).

Although caregiving can be perceived negatively, it can add satisfaction and purpose to life (Black *et al.* 2008, Ivey *et al.* 2013, Netto *et al.* 2009, Potgieter & Heyns 2006, Pretorius *et al.* 2009, Vellone *et al.* 2012, Williams *et al.* 2014). With appropriate support, education, and counseling the family caregiver can learn new skills to use to deal with life alterations and experience a caregiving reward (Sabat 2011). Taking care of a close one can bring with it a new kind of closeness in the relationship between the person diagnosed and the family caregiver (Sanders & Power 2009). If a family caregiver is able to accept the altering situation, focus on the good things still in life, and produce an empathetic and understanding attitude toward the person with the memory disorder, then the caregiving is a meaningful and positive experience (Shim *et al.* 2012). Despite the hardships, family caregiving can give existential meaning to the family caregiver's life, be a possibility for greater personal growth and deepen the



relationship with the person diagnosed (Netto *et al.* 2009, Sanders & Power 2009, Shim *et al.* 2013). Finding meaning through caregiving can be a positive coping strategy that buffers the burden of caregiving (McLennon *et al.* 2011).

#### **2.2.4 Memory disorder impacts family caregiver social roles**

A close one's memory disorder produces new demands on family caregivers and gradually changes a family's everyday life (Adams 2006, Lin *et al.* 2012, Phinney *et al.* 2013). A close relative's previous role turns into the caregiver role (Derksen *et al.* 2006, Phinney *et al.* 2013, Quinn *et al.* 2008, Sanders & Power 2009, Välimäki *et al.* 2012), and this new role can cause feelings of uncertainty, frustration, sadness or even more negative emotions (Adams 2006, Aubeeluck *et al.* 2012, Neufeld & Kushner 2009). Combining the different roles of a family caregiver, employee, and a member of the family e.g., the spouse or parent, requires reconciliation of the different demands in daily life. This is the case also for adult children who are caring for a parent (Edwards 2014, Stone & Jones 2009, Vreugdenhil 2014). Different family systems, such as blended families and later-life remarriages, posit additional challenges for spousal caregiving and may lead to a negative care-giving experience, particularly if there is a lack of support and conflicts between the different relatives (Sherman & Boss 2007, Sherman 2012).

A close one's memory disorder affects the nature of communication and also the relationships within the family, which also contributes to the feelings of loss (Ducharme *et al.* 2013, Purves & Phinney 2012, Sanders & Corley 2003), and may increase the family caregivers' sense of burden (Heimonen 2005). Progression of a memory disorder threatens the togetherness of a relationship and may have an influence on the closeness, mutual sharing, and the sense of 'we' in that relationship (Graham & Bassett 2006). Spousal relationship changes and marital closeness and intimacy are disrupted as mutual reciprocity diminishes (Adams 2006, Aubeeluck *et al.* 2012, Davies *et al.* 2010, Ducharme *et al.* 2013, Eriksson *et al.* 2013, Galvin *et al.* 2005, Hayes *et al.* 2009, Heimonen 2005, O'Shaughnessy *et al.* 2010, Quinn *et al.* 2008, Vernooij-Dassen *et al.* 2006). Spouse caregivers must balance between meeting the needs of their own lives and that of their partner, and due to these necessary alterations, they constantly must re-position themselves in relation to the spousal relationship and their spouse (Galvin *et al.* 2005, O'Shaughnessy *et al.* 2010). However, there are also positive aspects of taking care of a close one, as doing so can increase closeness and

improve the relationship with the care recipient and even bring family members closer together (Adams 2006, Aubeeluck *et al.* 2012, Galvin *et al.* 2005, Netto *et al.* 2009, Välimäki *et al.* 2012). In a positive co-operative relationship between the family caregiver and the person with the memory disorder, positive reciprocity, mutual respect, understanding, and trust will prevail, and the care receiver will not be considered merely an object and the caregiver will be not be perceived as an overseer (Graham & Bassett 2006).

Memory disorder also affects the social relationships outside family, and family caregivers often experience a social stigma toward their relative and themselves (Daly *et al.* 2013, Navab *et al.* 2013, Stone & Jones 2009, Vaingankar *et al.* 2013, Werner *et al.* 2010), which can increase the burden that family caregivers experience (Werner *et al.* 2012). Being responsible for a close family member can be binding for the family caregiver and decrease all social relationships (Daly *et al.* 2013, Quinn *et al.* 2008). When the social network diminishes, family caregivers may feel isolated (Aubeeluck *et al.* 2012, Neufeld & Kushner 2009, Quinn *et al.* 2008).

### **2.2.5 The influence of age on life of the family caregiver**

There are certain differences in the challenges that family caregivers of early-onset memory disorder experience compared to the family caregivers of late-onset memory disorder (Lockeridge & Simpson 2013, van Vliet *et al.* 2010). The shift into becoming a family caregiver can be especially demanding for the caregivers of younger patients (Ducharme *et al.* 2013) and they often experience greater negative outcomes than do the caregivers of older patients (Svanberg *et al.* 2011, van Vliet *et al.* 2010).

Early-onset memory disorder influences the entire family system (Svanberg *et al.* 2011, van Vliet *et al.* 2010). Caregivers of younger people face alterations in family roles and relationships, which can cause emotional problems and conflicts between all family members (Ducharme *et al.* 2013, Heimonen 2005, van Vliet *et al.* 2010). Younger family caregivers encounter challenges that are also related to their other responsibilities and roles outside family, their employment, and their family's financial issues (Heimonen 2005, van Vliet *et al.* 2010). There are special impacts for families with children (Harris & Keady 2004). Teenagers who participate in the care of a parent with this diagnosis face a challenge of balancing between being a child and a supervising caregiver. They need to form a new kind of relationship with their parent and take on more adult responsibilities. (Nichols

*et al.* 2013, Svanberg *et al.* 2010). However, although caregiving brings increased responsibilities, negative emotions and caregiving challenges for the children, they also see it as rewarding experience that brings all family members closer together (Nichols *et al.* 2013). Furthermore, having to recognize the nature of social stigma and being socially isolated is evident especially in cases of early-onset memory disorder (Ducharme *et al.* 2013, Harris & Keady 2004, Lockeridge & Simpson 2013).

### **2.2.6 Factors that promote family caregiver coping**

Taking care of a close family member with memory disorder is a demanding task that can involve several physical and mental stressors in that daily care (Pretorius *et al.* 2009, Shaji *et al.* 2003, Taşçı *et al.* 2012, Vaingankar *et al.* 2013, Zuccella *et al.* 2012) and cause burdens, grief, suffering, and psychosocial problems for family caregivers (Kamiya *et al.* 2014, Meuser & Marwit 2001, Sanders & Corley 2003, Välimäki *et al.* 2012, van Vliet *et al.* 2010) and thus compound family caregivers' vulnerability (O'Dwyer *et al.* 2013, Välimäki *et al.* 2009). Family caregivers have a need for emotional support as well as informational and practical support (Neufeld & Kushner 2009, Shaji *et al.* 2003, Stokes *et al.* 2014, Vaingankar *et al.* 2013). Concentrating on a spouse's cognitive impairment can also take precedence over the family caregiver's own needs (Eriksson *et al.* 2013).

Strategies that foster family caregiver coping with the disorder include practical, social and emotional factors, such as seeking information and support and engaging in meaningful activities (Bunn *et al.* 2012, O'Dwyer *et al.* 2013, Prorok *et al.* 2013, Shim *et al.* 2013, Välimäki *et al.* 2012). Supportive family relationships and shared responsibility reinforce the family caregivers' ability to cope and improves their wellbeing (Adams 2006, Aubeeluck *et al.* 2012, Derksen *et al.* 2006, Eriksson *et al.* 2013, Ford *et al.* 2013, Ivey *et al.* 2013, Lin *et al.* 2012, Morgan *et al.* 2014, O'Dwyer *et al.* 2013, Pretorius *et al.* 2009, Shaji *et al.* 2003, Shim *et al.* 2013, Vaingankar *et al.* 2013, Vellone *et al.* 2012, Williams *et al.* 2014). Social support from a wider social network and formal services is also important for family caregivers (Adams 2006, Aubeeluck *et al.* 2012, Bakker *et al.* 2010, Ford *et al.* 2013, Heimonen 2005, Ivey *et al.* 2013, Lee & Smith 2012, Lin *et al.* 2012, Neufeld & Kushner 2009, O'Dwyer *et al.* 2013, Potgieter & Heyns 2006, Pretorius *et al.* 2009, Quinn *et al.* 2008, Shim *et al.* 2013, Vellone *et al.* 2012). However, support from social networks or health care professionals is

not always seen as a positive element, if it is inadequate or fails to meet the expectations of the family caregivers (Neufeld & Kushner 2009, Neufeld & Harrison 2003, Neufeld *et al.* 2007, Stokes *et al.* 2014, Williams *et al.* 2014). Further, it is not always easy for family caregivers to accept help from other people or even from health care services as both can cause ambivalent feelings and a sense of failure concerning their caring duties (Bakker *et al.* 2010, Eriksson *et al.* 2013).

Dysfunctional coping strategies, such as avoidance and denying the situation, predispose caregivers to burdens and distress and can pose a threat to successful caregiving (Zuccella *et al.* 2012). Caregiver depression and distress will affect their feelings of being able to cope with different situations and take advantage of available resources (Välimäki *et al.* 2009). However, family caregivers' abilities to face these difficulties and their own personal characteristics, such as optimism, flexibility, determination and compassion, are factors that will reinforce their resources and abilities to manage the changes in family life (Che *et al.* 2006, Kindell *et al.* 2014, O'Dwyer *et al.* 2013, Shim *et al.* 2013, Williams *et al.* 2014). Finding an alternative viewpoint to such difficulties, maintaining hope and optimism, use of humor, accepting one's own situation, and considering it to be more fortunate than that among other caregivers can help promote family caregivers' ability to cope well (Pretorius *et al.* 2009, Williams *et al.* 2014). Faith and spirituality can also be factors that support family caregiver coping (Che *et al.* 2006, Lee & Smith 2012, O'Dwyer *et al.* 2013, Potgieter & Heyns 2006, Sanders & Corley 2003, Shim *et al.* 2013). Family caregivers may also consider that medication can bring hope by slowing down the progression of the symptoms (Adams 2006, Morgan *et al.* 2014).

A close one's memory disorder affects the family caregiver's future orientation and brings with it various negative feelings, i.e., fear, anxiety, uncertainty, despair, and resignation (Bunn *et al.* 2012, Derksen *et al.* 2006, Heimonen 2005, Navab *et al.* 2012, Pretorius *et al.* 2009, Quinn *et al.* 2008, Vaingankar *et al.* 2013). Fear of the future concerning the progression of the disorder and the possible increased burden of caregiving can affect family caregivers' sense of having a good quality of life (Navab *et al.* 2012, O'Shaughnessy 2010 *et al.*, Välimäki *et al.* 2012, Vellone *et al.* 2012, Williams *et al.* 2014). Living one day at a time, focusing on positive things in life, and taking joy in the moment are all factors that help express family caregivers' coping mechanisms and acceptance of the truth of the situation (Pretorius *et al.* 2009, Quinn *et al.* 2008, Sanders & Corley 2003, Shim *et al.* 2013). Adapting to any

altering life situation can be seen as a possibility to learn new things about life. (Heimonen 2005).

### **2.3 Summary of the literature**

For those with the diagnosis and their family caregivers, living with memory disorder is a process that has different phases. The diagnosis occurs at one point in the illness trajectory. However it is preceded by individual experiences of gradually becoming aware of the symptoms and looking for an explanation of them. Entering into medical examinations is not always a straightforward process, and close relatives often have to play a significant role in encouraging the person to seek help from professionals. Confirmation of the diagnosis is a shock as well evoking a range of negative feelings for both the person with the condition and those in the person's immediate network. It destabilizes familiar elements in both individuals' lives and their orientation towards the future. However, having an explanation for the uncertainty and understanding the reason for ongoing recognized difficulties also enables those with the diagnosis and their family caregivers to adjust to their altering lives and re-orient toward the future.

Living with a memory disorder means facing losses and changes in many different domains of the individuals and families' lives. Memory disorder can influence a person's functioning and competencies, which then affects the sense of self and causes new demands in terms of social relations, roles, and responsibilities both within a family and its wider social network. A close one's memory disorder creates new demands for the caregivers, producing several new stressors in their daily lives. Having sufficient practical and emotional support and maintaining meaningful social relations are worthwhile means that can foster the individual's coping with their altering life. The ability to face difficulties, focus on the positive things in life, and find a new kind of closeness in relationships are also elements that promote coping with the disorder. It is notable as well that although these elements are somewhat similar among people of different ages, individuals and families with early-onset memory disorder will face unique experiences that produce different challenges in their lives.

The characteristics of the previous research on living with memory disorder from the viewpoints of patients and their family caregivers are summarized in Appendix 1. This summary shows that most of the studies are cross-sectional ones focusing on the experiences of people older than 60 and their family caregivers. More than half of the studies have focused solely on the caregivers'

experiences and in one-fourth of the studies, the study sample consisted solely of people with the memory disorder. Approximately in one-fifth of the studies, the study participants included both patients and their close relatives. This statistic implies that the family caregivers' experiences have been of the most interest, and the research concerning families' interpersonal processes remains scarce. The family caregivers in these studies were usually spouses and seldom other close relatives, such as teenage or adult children. The most common data collection method in the qualitative studies was interviews, which were usually carried out as individual or joint interviews. The most common data analysis methods were a range of qualitative content and thematic analysis methods. Grounded theory methodology and phenomenology were also frequently used approaches. The greatest number of studies were conducted in Anglo-American countries (United Kingdom, U.S. and Canada). A number of studies have also been carried out in European countries, such as the Netherlands and Belgium, but only a few in the Nordic countries. On the grounds of this knowledge, it is necessary to produce data that is culturally applicable to the Finnish social and health care system as well as nursing education.

### **3 Purpose of the study and the research questions**

The purpose of this study was to produce a substantive theory that describes the mutual processes of managing life after disclosure of a diagnosis of progressive memory disorder from the viewpoints of those with that diagnosis and their family caregivers.

The following research questions were thus addressed:

1. What are the concepts and their properties that demonstrate the mutual processes of managing life with a memory disorder?
2. How are these concepts related to each other?
3. What kind of substantive theory emerges from examining the experiences of those with the diagnosis and their family caregivers when managing life with a memory disorder?





## 4 Methodology

### 4.1 Grounded theory as the methodological background

Grounded theory is a qualitative methodology for generating theory that is grounded in data which is systematically gathered and analyzed using a constant comparative method (Charmaz 2011, Corbin & Strauss 2008, Engward 2013, Hall *et al.* 2013, Strauss & Corbin 1998). Determining a theory is also understood as a developing process rather than a final product. With constant comparative analysis, it is possible to generate either a substantive or formal theory, which can both be considered as middle-range theories. (Glaser & Strauss 1967). Although grounded theory methodology does share some similarities with other qualitative methodologies the major difference is an emphasis on theory development (Strauss & Corbin 1998).

The foundation of grounded theory methodology dates back to the 1960's when Glaser and Strauss published their pioneering book titled *The Discovery of Grounded Theory* for generating theory inductively from data (Glaser & Strauss 1967). The roots of grounded theory rest in American sociology where at that time there were tensions between inductive qualitative and deductive quantitative research. Grounded theory legitimized and enhanced researchers' interest in qualitative research in sociology from where it then spread into nursing science. (Charmaz 2008, Pawluch & Neiterman 2010). Grounded theory methodology has become a popular approach in nursing science, as it is suitable for building a sound theoretical base for nursing (Elliott & Lazenbatt 2005). It also has a health-related focus, since originally Glaser and Strauss were interested in dying hospital patients and were also involved in training nurse researchers (Pawluch & Neiterman 2010).

Grounded theory methodology has evolved over the decades (Bryant & Charmaz 2010, Hall *et al.* 2013). Since the late 1980's, Glaser and Strauss started to have divergent views of the methodology which led to disagreement between them on how to produce grounded theory (Pawluch & Neiterman 2010). Glaserian grounded theorists saw Straussian grounded theory as a fundamentally different method from original grounded theory (Stern 1994). Cutcliffe (2005) proposed that it was necessary to delineate pure Glaserian grounded theory from modified grounded theory. Glaser criticized Strauss for moving the grounded theory approach back from theory generation to theory verification where using a

complex analytical procedure, the researcher forces the data instead of allowing the theory to emerge naturally (Kelle 2010, Pawluch & Neiterman 2010). Stern (1994) realized that the schism between Glaser and Strauss indeed led to an erosion of grounded theory.

Furthermore, postmodernist thinking has influenced the recent versions of the grounded theory approach (Hall et al. 2013, Pawluch & Neiterman 2010). Constructivist grounded theorists understand that reality is both multiple and complex, which requires an active and reflective researcher working in an emergent research process (Charmaz 2008, Charmaz 2011) wherein study participants' stories are listened to as openly as possible (Mills et al. 2006). There have also been some efforts to combine different analytical processes. Chen & Boore (2009) proposed a synthesized technique for grounded theory in nursing research, which offers a multi-step coding process and reflects Glaserian, Straussian and Charmazian's premises for grounded theory.

Grounded theory methodology was selected as an approach for this study since it is suitable for capturing social processes from actors' perspectives (Corbin & Strauss 2008, Hall *et al.* 2013, Strauss 1987, Strauss & Corbin 1998). Further, the methodology is well suited to research focused on human behavior related to health, developmental transitions, and situational challenges (Wuest 2007) as well as on questions of how people manage their lives in the context of difficult health challenges (Schreiber 2001), indeed the major interest in this study. Grounded theory methodology is also justified for this study since it is useful for any research where a new perspective is needed and sought (Glaser & Strauss 1967, Schreiber 2001, Wuest 2007).

The background of the grounded theory approach rests in symbolic interactionism and pragmatism (Charon 1998, Corbin & Strauss 2008, Hall *et al.* 2013, Pawluch & Neiterman 2010, Wuest 2007). Symbolic interactionism focuses on the social interactions between people where human beings are understood as active persons who influence one another. Based on this understanding, human actions are caused by social interaction but also through each person's own thinking and interaction with the self and the definition of the situation. (Charon 1998). The basic assumption in this research is that living with memory disorder is socially constructed. Therefore, the chosen methodology was justified for this study which focuses on the shared processes for managing life within a family following a diagnosis of memory disorder.

The application of grounded theory, as presented by Strauss (1987) and Corbin and Strauss (2008), was the adapted approach used in this study.

According to Strauss (1987) three essential aspects of any inquiry are induction, which leads to the discovery of a hypothesis; deduction, which consists of drawing on implications from the determined hypothesis; and verification, which links the hypothesis with new data and new coding. In Straussian grounded theory, a researcher will bring both insights and experience to the analysis of the gathered data (Pawluch & Neiterman 2010) and use abductive reasoning (Bryant & Charmaz 2010). As the researcher herein has had previous experience and background knowledge of the phenomenon, it was not realistic to start theory building without some preconceptions, as Glaserian grounded theory requires (Pawluch & Neiterman 2010). Further, Straussian grounded theory provides concrete steps for the researcher in the analysis process (Corbin & Strauss 2008), which will be easier for a novice researcher to employ than using Glaserian grounded theory (Kelle 2010). In addition, the use of computer-assisted data analysis software is feasible for Straussian grounded theory (Corbin & Strauss 2008) but not recommended for a Glaserian orientation (Holton 2010). For these reasons, Straussian grounded theory was selected as the methodology for this study.

Grounded theory methodology has been adapted for different kind of studies and disciplines. This adaptation, however, may have brought forth the risk of misunderstanding the methodology or using it inappropriately (Strauss & Corbin 1998). Stern (1994) warns of pseudo-grounded theorists who muddle the methods and do not do real grounded theory study, although claiming to do so. Despite these different ways of understanding the grounded theory approach, Pawluch & Neiterman (2010) sees that the essential idea when using grounded theory is “the notion of trying to understand human experience by becoming intimately familiar with those we are studying”. Hood (2010) stated that the main principles of all three brands on grounded theory, i.e., Glaserian, Straussian and Charmazian, are a constant comparison of data, theoretical sampling, and a theoretical saturation of categories, which became the premises in this study.

## **4.2 Study participants**

Eight families participated in this study. The study participants (Table 3) were people with diagnosed memory disorder (n=8) and along with their family caregivers (n=8), were recruited from the memory clinic at the Oulu University Hospital. Five of the patients were women, and three were men. Six were diagnosed with Alzheimer’s disease, and two had a diagnosis of Lewy Body

dementia. Their age varied between 51–74 years during the first interview. Family caregivers were spouses, with the exception of one caregiver who was a daughter. Details of the participants' diagnoses and Mini-Mental State Examination (MMSE) scores were obtained from patient records and are presented in Table 4.

A purposive sampling procedure was used to recruit families for the study. The criteria for recruitment were broad and the interest to participate was gathered from those who had received a diagnosis of progressive memory disorder and their close relatives who acted as family caregivers and were able and willing to participate in the study. The study participants were recruited in two phases. First, the contact nurse from the memory clinic asked about tentative interest from those clients whom she then evaluated as potential study participants and informed about the study. Those who were interested in participating gave written permission for the researcher to contact these same individuals within a week. In the second phase, the researcher contacted and informed them in more detail about the study and asked for their willingness to take part in the study. The first interview was scheduled with those who were inclined to participate. The purpose of this procedure was to protect families' privacy and give all potential participants enough time to consider their participation during the diagnostic phase. The procedure used for recruiting the study participants is described in more detail in the original Article I.

Although the term 'dementia' is widely used in the English professional and scientific literature to mean progressive memory disease, the term 'memory disorder' is used here instead because the study participants were newly diagnosed and their condition was in its early stages. Thus any negative connotation could be reduced. The term 'dementia' often refers to the later stages of the disorder and holds a stereotypical connotation, namely that of being an older person's condition (Alzheimer's Disease International 2012). Further still, the term 'memory disorder' is in accordance with the evolution of the use of such terms in Finnish professional and scientific terminology, as there has been a shift from using 'demented person' to using 'dementing person' and further yet to using 'person with memory disease / disorder'. In addition, the term 'memory disorder' is consistent with the terminology used in Finland's national memory programme (Ministry of Social Affairs and Health 2013a). The term 'family caregiver' is used to imply those close relatives, i.e., spouse or adult child, who act as the main support for the person already diagnosed.

**Table 3. Characteristics of the study participants**

Study participant	Person with memory disorder (PMD)						Family caregiver (FC)				
	Gender	Age (years) <sup>1</sup>	Diagnosis <sup>2</sup>	MMSE <sup>3</sup>	First symptoms <sup>4</sup>	Occupation before diagnosis	Occupation after diagnosis	Study participant	Kinship	Age (years) <sup>1</sup>	Occupation during data collection
PMD1	female	65	AD	27/30	6 years back	disability	old age	FC1	spouse	73	old age
PMD2	female	74	AD	21/30	2 years back	pensioned	pensioned	FC2	spouse	82	pensioned
PMD3	female	59	AD	20/30	1 year back	employed	sick leave, disability	FC3	spouse	63	unemployed, early old age
PMD4	male	51	AD	14/30	2 years back	part-time	sick leave, disability	FC4	spouse	53	pensioned
PMD5	female	57	LBD	18/30	1 year back	employed	disability	FC5	daughter	39	house wife, paid family caregiver
PMD6	female	68	AD	20/30	3 years back	old age	sick leave, disability	FC6	spouse	63	employed, paid family caregiver
						pensioned	old age				early old age
						pensioned	pensioned				pensioned

Study participant	Person with memory disorder (PMD)						Family caregiver (FC)				
	Gender	Age (years) <sup>1</sup>	Diagnosis <sup>2</sup>	MMSE <sup>3</sup>	First symptoms <sup>4</sup>	Occupation before diagnosis	Occupation after diagnosis	Study participant	Kinship	Age (years) <sup>1</sup>	Occupation during data collection
PMD7	male	59	LBD	26/30	2 years back	employed	sick leave, disability	FC7	spouse	56	employed
PMD8	male	55	AD	20/30	same year	unemployed	pensioned disability, pensioned	FC8	spouse	52	unemployed, paid family caregiver

<sup>1</sup> Age during time of diagnosis, <sup>2</sup> Abbreviations of diagnosis: AD = Alzheimer's disease, LBD = Lewy body memory disease, <sup>3</sup> MMSE-scores during time of diagnosis, <sup>4</sup> First symptoms reported either by self or by close relative

**Table 4. The MMSE-scores of persons with memory disorder**

Person with memory disorder	Gender	Age (years) <sup>1</sup>	Diagnosis <sup>2</sup>	MMSE-scores <sup>3</sup>					
				Baseline <sup>4</sup>	6–11 months	12–24 months	25–36 months	37–48 months	49 months or more
PMD1	female	65	AD	27/30		27/30			
PMD2	female	74	AD	21/30	19/30	22/30			
PMD3	female	59	AD	20/30	19/30				
PMD4	male	51	AD	14/30	16/30		3/30		
PMD5	female	57	LBD	18/30	22/30	18/30	17/30	16/30	13/30
PMD6	female	68	AD	20/30		24/30	25/30	24/30	21/30
PMD7	male	59	LBD	26/30	25–29/30	28/30	27/30	25/30	
PMD8	male	55	AD	20/30	13/30		9/30	4/30	

<sup>1</sup> Age during time of diagnosis, <sup>2</sup> Abbreviations of diagnosis: AD = Alzheimer's disease, LBD = Lewy body dementia, <sup>3</sup> The development of MMSE-scores after diagnosis, <sup>4</sup> Baseline MMSE-scores during time of diagnosis

### **4.3 Data collection**

Data for the study were collected using qualitative in-depth (Johnson 2002) interviews that at the outset were low structured interviews and then became more focused semi-structured interviews as the data gathering proceeded (Hesse-Biber & Leavy 2011). Conversational interviews were conducted in the homes of the study participants during December 2006–April 2009. Interviews were conducted by the researcher, audio-recorded, and then transcribed verbatim. Furthermore, unstructured observations of the study participants' interactions and nonverbal expressions of emotions were conducted during the research interviews to gather additional data for precise interpretation of the interview data (Angrosino & Rosenberg 2011, Corbin & Strauss 2008). These observations were written down in a research diary after the interviews.

The data were collected in four phases within 20–24 months from 7 families. One family participated twice during an 11-month period, a mutual decision of the researcher and the family since that person's condition progressed and notable difficulties in verbal expression appeared. The total number of interviews was 40, and they were carried out mostly as joint interviews with both study participants present. The aim was to carry out the data collection by combining both the individual and joint interviews (Pratt 2002); however, compromises were made according to the study participants' wishes. Flexibility is imperative when conducting a research study that is ethical in nature to preserve the personhood of study participants (Cowdell 2006). The first round interviews with the families were conducted one week – six months after the diagnosis of the memory disorder was confirmed. Follow-up interviews in the second, third, and fourth rounds were conducted 6–9 months after the previous interviews. (See Table 5)



**Table 5. Data collection periods, number of interviews conducted, and duration of interviews**

Conducting of interviews	First-round interviews	Second-round interviews	Third-round interviews	Fourth-round interviews
Time frame	December 2006– October 2007	June 2007– September 2008	January–September 2008	October 2008– April 2009
Occurrence after diagnosis	1 week–6 months	6–12 months	13–19 months	20–27 months
Number of families interviewed	8	8	7	7
Number of interviews	8 joint interviews 9 individual interviews	8 joint interviews	7 joint interviews	6 joint interviews 2 individual interviews
Duration of interviews	45–165 minutes (average 108 minutes)	54–95 minutes (average 75 minutes)	58–185 minutes (average 100 minutes)	50–134 minutes (average 85 minutes)

The data collection followed the known principles of theoretical sampling (Corbin & Strauss 2008) although no new study participants were recruited after the first round of interviews (Morse 2007). Corbin and Strauss (2008) have pointed out that the basis for sampling is concepts, not persons, and what matters is that the questions to be asked in a next interview are based on what was discovered previously (Corbin & Strauss 2008). Collecting the data took place as a circular process where the preliminary data analysis informed subsequent data collection. Data collection became progressively focused, and emerging concepts were verified in the next scheduled interview. (Corbin & Strauss 2008, Elliott & Lazenbatt 2005).

The starting point for this study was a broad question about what it means to live with a progressive memory disorder. In a grounded theory –study this research question is broad and flexible, so that the researcher can obtain different perspectives on a topic (Corbin & Strauss 2008, Engward 2013, Smith & Biley 1997). The first interviews were thus directed by the following themes: 1) study participants’ previous episodes of life; 2) phases of recognizing the symptoms, seeking help and entering into medical examinations and getting confirmation of the diagnosis; 3) study participants’ everyday life; 4) their restorative means attempted in life; and 5) thoughts for the future. These broad themes were driven from the data from previous studies. The questions that guided the data collection sharpened, as the interviews proceeded and the researcher’s understanding

increased. The previous interview guided the next interview, and the emerging concepts were verified in later interviews (Corbin & Strauss 2008). The data were collected until sufficient saturation occurred on a conceptual level, according to the designated purpose of the study (Corbin & Strauss 2008, Morse 2007).

#### **4.4 Data analysis**

The transcribed interview material consisted of 1,378 A4-pages, produced as double line spacing. The data were analyzed using constant comparative analysis (Corbin & Strauss 2008, Strauss 1987) using QSR NVivo computer-assisted qualitative data analysis software (Versions 8 and 10). Computer software was used on a basic level to store, code, and analyze the data. As noticed earlier (Bergin 2011, Creswell & Creswell 2007, Korhonen *et al.* 2009, Morison & Moir 1998, St. John & Johnson 2000) computer software helps to handle large amounts of data in one place and allows the researcher to write insights and memos as these understandings emerge during data analysis. It also promotes management of the analysis process as it allows for going back and forth between the data, codes, concepts and memos without fear of losing the connection between these elements.

Preliminary analysis of the data took place during the data collection and is an essential feature of grounded theory research (Corbin & Strauss 2008, Elliott & Lazenbatt 2005). Data generated by each family in the first phase were analyzed more rigorously on a family basis, and the results were reported in the original Article II. Data gathered from the second, third, and fourth follow-up interviews were analyzed in chronological order using the separate viewpoints of both the person diagnosed and the family caregiver (original Article III). Analysis then proceeded further, and the results were merged to refine a descriptive substantive theory of the process of living with memory disorder during the first years after such a diagnosis.

The initial open coding of the interview data started with reading the transcribed text and picking the meaningful passages that described the phenomenon. Sensitizing questions (Corbin & Strauss 2008), such as “How do the study participants describe and define their life situation?”, “What does memory disorder mean to them?” and “Are their definitions and experiences the same or different and in what way?” were posed in relation to the data collected. The truly meaningful utterances consisted mostly of several sentences, so they were labelled with conceptual codes. In the phase called axial coding, these

conceptual codes were categorized by identifying both their similarities and differences as well as the dimensions of the experiences they offered. The codes were compared by asking more theoretical questions (Corbin & Strauss 2008), such as “How are the codes related to each other?”, “What are the larger structural elements in the data?” and “How did study participants’ experiences and actions change over time?” The categories were then named using a conjunctive concept. The categories and their connections were developed further during selective coding to find the basic social psychological process.

In this integration phase (Corbin & Strauss 2008), the core category was formulated, and the related concepts around it were outlined. Writing of memos to reflect theoretical ideas and interpretations and organize theoretical thinking took place throughout the analysis process. Notes on the observations supported the interpretation of the data. Constant comparisons as well as theoretical comparisons of data (Corbin & Strauss 2008) continued throughout the analysis process until the phase of writing the results. Therefore, although the coding phases are described here as separate phases, they took place as cyclical and also intertwined coding processes.

#### **4.5 Ethical considerations (original Article I)**

This study was carried out in accordance with the legislation stipulating medical research on persons (Medical Research Act 488/1999, Medical Research Decree 986/1999). The ethical procedure for the research was approved by the Ethical Committee of the Northern Ostrobothnia Hospital District (Eettmk: 107/2002, 241§ and Eettmk: 9/2006, 322§).

In this study, the informed consent to participate was confirmed in two ways. A formal informed consent procedure with a verbal and written description of the research, its purpose, procedure, risks, and benefits as well as specific voluntariness (Alzheimer's Association 2004, Cacchione 2011) was implemented during the first meeting with the study participants. Equal and dual consent procedure was undertaken where both the person with the memory disorder and the family caregiver gave signed personal consent to participate and permission to interview one another. Secondly, informed consent was reassured verbally before each interview, and all participants’ willingness to take part in the study were monitored and evaluated during the interviews. An ongoing consent process was significant in this kind of a longitudinal research, as the progressive nature of memory disorder could pose a challenge for evaluating assent and possible

dissent (Beattie 2007, Cacchione 2011, Slaughter *et al.* 2007). It was the researcher's conscious comprehension that each study participant understood the nature of the study and was able to express his or her assent or dissent concerning study participation throughout the study. None of the study participants wanted to end their participation, and all families were thus voluntarily involved throughout the study.

Even though occasionally the interviews brought out difficult issues that caused emotional distress, study participants still wanted to continue after a short break. After each interview the researcher asked the study participants how they had experienced the interview. Study participants indicated that they enjoyed the opportunity to tell their experiences to someone, similarly noticed in earlier studies (Cowdell 2006), and they also expressed a hope that their experience would be useful for others in the same situation. With the eighth family, it was a mutual agreement that their participation was limited to two interview rounds. The researcher assumed that further interviews with this family would not significantly bring any new information to the analysis and thus to the theory construction due to the progression of that person's memory disorder.

Because this study focused on emotionally sensitive experiences, and it was assumed that participants were living in a time of crisis, the procedure used in this study aimed specifically to protect the safety, well-being and autonomy of the vulnerable study participants (Liamputtong 2007). Therefore, the ethical principles of beneficence, non-maleficence, respect for the autonomy of study participants and justice toward them guided the entire research effort (Aita & Richer 2005, McIlpatrick *et al.* 2006, Smith 2008).

Ethical questions that occurred during the data collection were related to the altering situation of the study participants and to the role of the researcher, and these themes are discussed in more detail in the original Article I. The transitional process and the challenging life situation of the study participants due to their recently diagnosed progressive memory disorder challenged the researcher to find a means to minimize the distress and burden of all study participants. The fact that the interviews were conducted mainly as joint interviews according to the study participants' will called for methodological solutions that would promote each study participant's voice to be heard equally during joint interviews. Furthermore, the researcher needed to take into account the cognitive symptoms of the person with the diagnosis when striving to enable their voice to be heard despite any cognitive problems and difficulties in verbal expression. Conducting research interviews with vulnerable people as a nurse researcher demanded a

clarification of the researcher's role and fully understanding the elements of possible role conflict, as well as dealing with any emotional burdens due to the close interaction being undertaken with study participants and their rendition of very personal experiences. These ethical considerations and their methodological solutions are summarized in Appendix 2. These above-mentioned ethical concerns indicated that the researcher's ethical choices and methodological solutions be included in all phases of the study. As noted also earlier (Jokinen *et al.* 2002, Kylmä *et al.* 1999, Moore & Miller 1999) conducting ethically sound research requires careful preparation and planning as well as continuous ongoing reflection and assessment of all actions undertaken and decisions made throughout the entire study.



## **5 Results**

A substantive theory for managing life with a memory disorder was formulated from the gathered data. That theory is based on the results of the original Articles II and III, but also some unpublished data that were used to supplement the results. Categories and their subcategories form the concepts of this new theory. First the concepts and their properties are reported, and then the relationship between the concepts is described to provide overall picture of the theory in full.

### **5.1 Phases of the families' illness trajectory (original Article II)**

The study participant experiences on their path with the memory disorder contained phases where they first recognized worrying symptoms, then made a decision to seek professional help, got confirmation of the diagnosis of a memory disorder and sought new equilibrium in their lives. The families' illness trajectories had both individual and mutual dimensions, as family members concurrently dealt with their observations, experiences, and decisions both personally and collaboratively. The phases of the families' illness trajectory are described in more detail in the following chapters, and examples of their authentic citations are presented in Appendix 3.

#### **5.1.1 Recognizing the symptoms (original Article II)**

Although confirmation of the diagnosis was a mutual turning point in each family, the illness trajectory started earlier, as individuals with the memory disorder or their close relatives recognized alarming symptoms. Most of the study participants reported that they noticed the symptoms 1–2 years earlier. In one case, the family had lived with the uncertainty of the reason for symptoms they saw for about six years, while another family was awakened to the symptoms just recently, before they sought professional help and the diagnosis was confirmed (See Table 3).

The symptoms were commonly thought to be related to burnout, depression, other health problems or illnesses, or troubles in everyday life. Elderly study participants also viewed the symptoms as being related to their own ages. Progressive memory disorder was not the first explanation that the study participants thought to be the reason for the symptoms. Some families continued to live with the symptoms without thinking about the seriousness of them. For

some, it was also difficult to differentiate between normal forgetfulness and a progressive condition. The symptoms often evolved little by little, and families simply adjusted to the changes in their everyday lives. However, recognizing the symptoms was not always a conscious recognition even for the family caregivers. One family caregiver expressed how she had not realized that the changes had actually occurred already a few years before they actually sought professional help. In another family, the family caregiver indicated that she was not aware of her husband's difficulties at work before he stayed home on a sick leave.

### ***5.1.2 Seeking professional help (original Article II)***

Usually the families faced a trigger before the decision to seek professional help was made. Study participants either faced significant problems at work or home, or the difficulties accumulated over the course of some time. The decision to seek help from health care professionals was made within each family although family caregivers did play a significant role in motivating the person eventually to go for a clinical examination. Some families described how difficult it was for the person him-/herself to accept the need for closer examination. However, there were those who sought help on their own initiative even without revealing this action to their close relatives beforehand. Some families were followed up on by health care personnel for some time because of mild symptoms, but for the most part, the contact with the professionals led to broader clinical examinations and then to a diagnosis.

### ***5.1.3 Diagnosis as a mutual turning point (original Article II)***

Confirmation of the diagnosis was a mutual turning point for each family, as they received an explanation and became aware of the reason for the symptoms they had been living with for a while. Although the diagnosis had different personal meanings for the individuals in the family, it did concurrently form a shared concern for the whole family. The diagnosis was commonly experienced as a crisis and a stagnant experience for both the person diagnosed and the family caregiver, since it undermined the equilibrium of life, and caused feelings of sorrow and fear for the future. For those study participants who were employed, the diagnosis broke off their careers. This event undermined their self-esteem as a competent person, but on the other hand, they felt relief due to the substantial difficulties they had been facing at work. Diagnosis of a progressive memory



disorder was also an unexpected explanation, especially for some younger study participants, since for them, a memory disorder represented an older person's condition. Some family caregivers described how knowing the reason was a relief for them since it stopped the uncertainty they had experienced. However, for other families, the diagnosis was not an eminently tragic event, but actually just one episode among others. This was the case with families with other concerns in life, such as comorbidities, unemployment, or economic worries.

#### **5.1.4 Seeking a new equilibrium**

The diagnosis destabilized the family equilibrium and changed the course of families' lives. Memory disorder and its manifestation in daily life became a shared concern in the families, and they deliberately started to take the disorder into consideration in their everyday living. This change became evident, for example, in how families started to modify their living conditions, daily activities, nutrition, or exercising to meet the needs of the person diagnosed or the family as a whole. Those family caregivers who were employed also needed to consolidate their responsibilities at work and at home.

Families sought to find solutions to everyday challenges and the means to support the family's management of the disorder. Finding an alternative viewpoint for hardships was also one way that families sought to find a new balance for their lives. After confirmation of the diagnosis, the families gradually realized that life still goes on and they could still have an influence on their family's life. Their impression of the future was, however, rather pessimistic. Due to the progressive nature of the disorder, many families' efforts toward finding equilibrium had to be ongoing.

## **5.2 Restructure of roles and identity (original Articles II, III)**

Living with memory disorder and facing alterations in family life and social relations outside the family resulted in having to restructure the family members' roles and images of self. Study participants needed to adapt to new roles of being a spouse, parent, or adult child. The disorder had an impact also on the participants' other roles in life, such as that of a friend, relative, neighbor, or employee. Gradually their roles shifted toward that of caregiver and care receiver. For the individuals who were diagnosed, adjusting to their altering self was central in the process of learning to live with memory disorder, whereas for the

family caregivers, their adapting to the new caregiver role became essential. These factors became intertwined, thus producing a mutual adjustment process in the family. Study participants' experiences are described in more detail in the next two chapters, and examples of authentic citations are presented in Appendix 4.

### ***5.2.1 Adjusting to altering self (original Article III)***

For those with the diagnosis, the adjustment process was emotionally demanding, as they needed to orient themselves to losses, alterations in their functioning, accepting assistance from others, and facing personal feelings of unpredictable future. The adjustment process involved distress due to losses and fears, but also approving the recognition of their own situation and self, finding positive elements in life, valuing closeness and mutual sharing with their close relatives, and sustaining the feelings of hope. Acknowledging their own potential and resources, having a supportive social network, and focusing on the present were factors that promoted adjusting to the changes in their situations.

### ***5.2.2 Adapting to a new caregiver role (original Article III)***

The new role of caregiver brought about new responsibilities for the close relatives. Adapting to this new role contained both negative elements of distress, conflict and strain, due to the increased responsibility of daily activities, requirements for modifying their own activities, and the difficulties of assimilating to a new role and understanding the changes in a close one's behaviour. However, there were also positive elements of maintaining hope, appreciating togetherness, finding and sustaining optimism, and a commitment to be supportive in troubled times. Acknowledging the available resources of the person diagnosed and supporting his or her potential, having sufficient social support, and living in the present were factors that promoted family caregivers' positive adjustment while learning to live with the disorder.

## **5.3 Mutual processes for managing life with a memory disorder (original Articles II, III)**

Three subcategories 'Acknowledging available qualities and resources', 'Seeking meaningful social support' and 'Living for today' describe the means whereby both the individuals with the memory disorder and their family caregivers sought

a new equilibrium in an altered life. Managing life with a memory disorder contained both positive and negative elements and balancing hope and distress. Accepting an altered life with a memory disorder represented a hope-fostering adjustment. The subcategories of the mutual processes for managing life with the disorder are described in the following chapters and examples of authentic citations are presented in Appendix 5.

### ***5.3.1 Acknowledging available qualities and resources (original Article III)***

Families faced the inevitable changes due to the diagnosis that had caused them distress and concern. Regardless of these circumstances, families aimed to overcome the difficulties and strove for acknowledging available qualities and resources in their everyday lives in order to manage the disorder. Individuals with the disorder experienced personal losses in their functioning, which they considered a significant life-shift that caused sadness. Their opportunities for, and interest in, meaningful and independent activities were gradually reduced. However, they tried to aspire toward having a potentially positive existence. Family caregivers' responses to their situations were also two-fold. Their responsibilities for the individuals' and the whole family's well-being increased, which caused them feelings of stress and burdens. Family caregivers were challenged to balance the tasks of supporting their close one instead of merely focusing on their troubles and losses.

For people with the memory disorder, the means to make the most of their potential were related to activity and participation and self-determination. Meaningful daily activities, reciprocal help, and being regarded as a competent person still with potential were factors that promoted the managing of the altering self. It was also important for them to retain some autonomy and control concerning their own affairs, i.e., telling others about the diagnosis, treatment, and carrying on with duties. Sometimes this aspect caused tension in the family, as family caregivers needed to balance the independence and autonomy with solicitude and surveillance of the person with the disorder.

Families aimed to maintain an active lifestyle and made practical arrangements in order to manage their lives. Sometimes people with the diagnosis were concerned that these new arrangements caused a burden to their family caregivers. Some family caregivers focused on losses and described the conflicts due to a person's changing behavior and deteriorating abilities, altering roles and

interactions in the family, and constriction of their own personal lives which then caused a negative atmosphere to develop in the family. However, the family caregivers' supportive, understanding and encouraging attitude as well as their positive approach toward recognizing the needs of both the person with the diagnosis and themselves, promoted the family's well-being and management of the altering situation.

### **5.3.2 Seeking meaningful social support (original Article III)**

Adequate social support either from the immediate family or wider social networks, including social and health care professionals, was a significant factor in managing the altering life. On the contrary, support that did not meet the needs of study participants or was inadequate or person's withdrawal from social relationships left some individuals managing alone. It appeared that certain individuals with the disorder wanted to grieve alone, a choice that reflected either a desire to keep the diagnosis a personal matter, a need to maintain control over their personal concerns, feelings of shame, or simply stagnant sorrow. Few family caregivers described a lack of social support either from the relatives' side or from the professionals. Therefore, not all social support was experienced as a positive and restorative factor. Gradually these families' social contacts changed, and their lives became more home centered, as the cognitive difficulties affected individuals' functioning in social situations and family caregivers' opportunities to enjoy activities outside the home became restricted due to increased responsibilities.

However, emotional support from close relatives, such as spouses, children, and grandchildren, became an important resource. People with the diagnosis expressed the importance of being accepted as they now were. Facing these alterations was a shared effort, and some families described how the difficulties made the mutual relationships stronger. Family caregivers' role in providing practical support to those with the memory disorder was essential. Assisting in daily activities and social interactions and promoting safety supported the diagnosed individuals' potential in everyday life. Further, for some families, the wider circle of acquaintanceship, such as other relatives and neighbors, was an important source of emotional and practical support.

Peer support seemed to be more significant to family caregivers than for the people with the diagnosis. Sharing experiences with others in the same situation was an important source of emotional and informational support. However, some

individuals with the disorder expressed the view that they did not have a need or interest in participating in a peer support group, even though they already had had experience with it. Study participants had double-edged experiences with support from social and health care professionals: Some families felt that they were heard and understood and given useful information by them, while for others, that support did not meet their expectations.

### **5.3.3 *Living for today (original Articles II, III)***

The progress of the memory disorder and its effects on families' lives caused uncertainty and fear of an unknown future. Some study participants were concerned about how family caregivers would manage them. Families counterbalanced this unfavorable image of the future by having a mindset for living one day at a time, taking things as they come, and focusing on the positive things in their altering life situation. Hopes for the future were related to wishes that life would stay the same as long as possible and the progression of the condition would be slow. However, hopes for the future were rather limited. Families focused on the remaining possibilities, strengths and capabilities to maintain their optimistic spirit. They had the objective to live a common everyday life and carry out familiar and meaningful daily activities. Family caregivers also played an important role in encouraging and supporting the person diagnosed with the disorder.

## **5.4 Accepting memory disorder as part of family life and the substantive theory of managing life with a memory disorder**

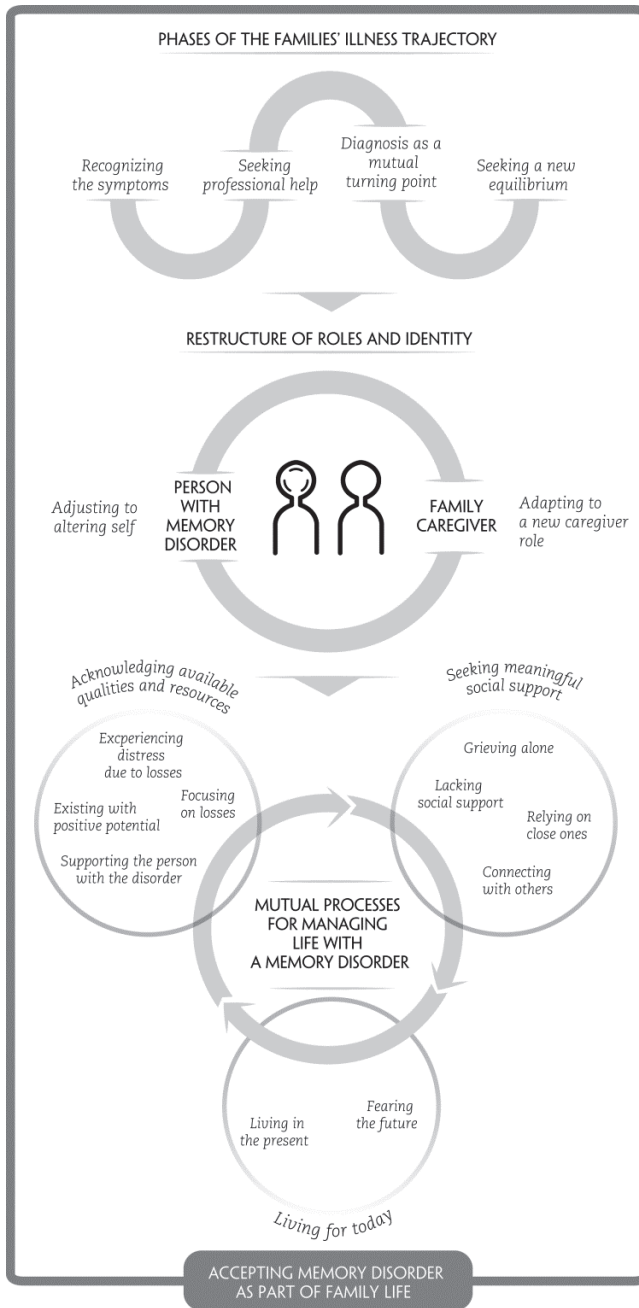
A core category, '*Accepting memory disorder as part of family life*' was formulated from the gathered data. The core category bound together the concepts of the substantive theory, i.e., the categories and their subcategories (Corbin & Strauss 2008, Holton 2010) and described the central psychosocial process within families when having to come to terms with altering life due to the memory disorder. Accepting a memory disorder as part of the family's life represented a hope-fostering adjustment, where family members collaborated to respond to changes without denying or giving up, but instead confronting the reality to the best of their ability and resources.

Families lived through different *phases of their illness trajectory*, and that trajectory began when those with the memory disorder or their close relatives

recognized alarming symptoms. However, the diagnosis of a progressive memory disorder was a turning point in the families' illness trajectories, as it shook the equilibrium of family life, but also offered an explanation for the uncertainty of symptoms. The diagnosis changed the courses of lives of individuals and indeed the whole family and led these families to seek a new equilibrium in life.

The altering life situation and deterioration of functional capacity challenged the people with the diagnosis and the family caregivers to *restructure their roles and identities*. For the person with the memory disorder, adjusting to an altering self was a central theme in this process, whereas for the family caregiver, adapting to the new role of caregiver was essential. These processes were intertwined and thus affected each other. *Mutual processes for managing life with a memory disorder* comprised the following factors: Acknowledging available qualities and resources, seeking meaningful social support, and living for today. Managing life with a memory disorder meant balancing hope and distress, and thus, they contained both positive and negative elements.

The substantive theory of managing life with a memory disorder describes the mutual processes that individuals with the diagnosis and their family caregivers face for the altering situation in the family and the means that they use to manage life during the first years living with the memory disorder (See Figure 1).



**Fig. 1. Diagram of the substantive theory of managing life with a memory disorder.**





## **6 Discussion**

### **6.1 Overview of the theory**

The purpose of this study was to produce a substantive theory of the mutual processes for managing life after the disclosure of a diagnosis of memory disorder from the viewpoints of those with the diagnosis and their family caregivers. The results brought forward how confirmation of the diagnosis of a progressive memory disorder is a turning point in each family's illness trajectory, thus changing the course of life for the individuals with the diagnosis and the whole family. In this respect, the results support the previous studies. Families' efforts toward finding equilibrium after the diagnosis are ongoing. A central notion in the produced theory is that an illness trajectory has both individual and mutual dimensions for family members. For the persons who are diagnosed, adjusting to an altering self becomes central in the process of learning to live with an altering life, whereas for the family caregivers, adapting to a new caregiver role is essential. These processes of restructuring roles and identity become intertwined, thus affecting each other.

The theory emphasizes the interpersonal processes and family member collaboration when seeking a new balance and managing life with a memory disorder. In this regard, the study brings new insight to the previous knowledge base, as intrapersonal processes have been of keen interest. According to the formulated theory, managing life with a memory disorder comprises three factors, all of which have both positive and negative elements of hope and distress. These factors are connected to family members' desire and aim to acknowledge available qualities and resources and seek meaningful social support, and also their objective to live in the present.

Although similar factors have been presented in earlier studies, the offered theory contributes current knowledge, as it presents a compilation of these mutual management strategies within the family. Accepting memory disorder as part of a family's life represents a hope-fostering adjustment and forms the theory's core category by describing the central psychosocial process within families when they must come to terms with altering life due to a memory disorder. Study participants in this study were rather young persons, mostly 65 years of age or younger. The results indicate that the life situations connected to age have an

influence on the experiences and processes of managing that life for both those with the diagnosis and their family caregivers.

The relevant literature is synthesized to the findings in the following chapters. First the categories and their subcategories are contextualized with earlier studies. Then the formulated substantive theory of managing life with a memory disorder and its core category, namely, 'Accepting memory disorder as part of family life', are discussed.

### **6.1.1 Phases of the families' illness trajectory**

#### *Recognizing the symptoms and seeking professional help*

Before the diagnosis of a memory disorder was confirmed, families lived through different phases in their illness trajectory by recognizing symptoms and making the decision to seek professional help. A similar transitional process has been described in earlier studies (Adams 2006, Ducharme *et al.* 2013, Galvin *et al.* 2005, Heimonen 2005, Johannessen & Möller 2013, Leung *et al.* 2011, Morgan *et al.* 2014, Parsons-Suhl *et al.* 2008, Samsi *et al.* 2014, Steeman *et al.* 2006, Välimäki *et al.* 2012, Werezak & Stewart 2002).

Recognizing the symptoms did not always straightforwardly lead to outright contact with professionals. Families did not acknowledge that the reason for the observed symptoms was a serious cognitive condition. The symptoms were thought to be related to other problems, such as burnout or depression, or they were seen as normal forgetfulness or part of aging. Previous research has brought forth similar reasons, such as being the barriers to seeking help (Bunn *et al.* 2012, Chrisp *et al.* 2012, Heimonen 2005, Hughes *et al.* 2009, Koehn *et al.* 2012, Leung *et al.* 2011, McCleary *et al.* 2013, Werezak & Stewart 2002). Interestingly it was a notable remark that some close relatives had not noticed any dramatic changes in the close one's functioning, a finding that previous studies seldom have produced. It may be that the troubles in daily life occurred mainly at work where the demands are always different than in the home environment.

As noted earlier (Adams 2006, Bunn *et al.* 2012, Chrisp *et al.* 2012, Heimonen 2005, Leung *et al.* 2011, Morgan *et al.* 2014) it was found that when individual him-/herself or someone from the immediate family acknowledged the severity of the symptoms, experienced a clarity that the problems had accumulated, or there was a trigger event, then the contact with professionals was

made. Close relatives often played an important role in seeking help, a finding also supported by previous studies (Bunn *et al.* 2012, Chrisp *et al.* 2012, Heimonen 2005, Leung *et al.* 2011, McCleary *et al.* 2013, Morgan *et al.* 2014, Samsi *et al.* 2014, Välimäki *et al.* 2012).

### *Diagnosis as a mutual turning point*

Confirmation of the diagnosis was a turning point for the families, leading them to seek a new equilibrium. Diagnosis provided an explanation for the symptoms and now became a shared concern for the whole family. In this respect, the findings corroborate earlier studies that indicate that confirmation of the diagnosis is a significant phase in a family's life, thus initiating the adjustment process of the diagnosed individuals and the whole family (Beard 2004, Clare *et al.* 2008, Gilmour & Huntington 2005, Heimonen 2005, Langdon *et al.* 2007, Morgan *et al.* 2014, Steeman *et al.* 2006, Stokes *et al.* 2014, Välimäki *et al.* 2012, Vernooij-Dassen *et al.* 2006, Werezak & Stewart 2002). This finding emphasizes the importance of informational and emotional support and skillful patient- and family-centered tailored practices when disclosing this diagnosis (Byszewski *et al.* 2007, Fisk *et al.* 2007, Husband 1999, Wilkinson & Milne 2003).

Diagnosis of a memory disorder was commonly experienced as a negative event that threatened not only the individual's well-being but also the whole family. However it had somewhat different meanings for study participants: Some expressed that the diagnosis was a crisis that evoked feelings of fear and sorrow, and for others it was a relief, as it provided an explanation for their unawareness. The results in this respect confirmed the previous research (Clare *et al.* 2008, Derksen *et al.* 2006, Ducharme *et al.* 2013, Harris & Keady 2009, Heimonen 2005, MacQuarrie 2005, Parsons-Suhl *et al.* 2008, Potgieter & Heyns 2006, Samsi *et al.* 2014, Steeman *et al.* 2006, Välimäki *et al.* 2012, Vernooij-Dassen *et al.* 2006, Werezak & Stewart 2002, Williams *et al.* 2014).

Interestingly some of the study participants expressed the view that the diagnosis was not a shattering event in their life, indeed a finding that the previous research has seldom brought forth. Expressing how the diagnosis was not that problematic and did not have a great impact on a family's life may have been the result of having adjusted to the trouble in life already (Hulko 2009), but also perceiving the symptoms as being a marker of aging (Settersten & Trauten 2009) or deciding to maintain their normality and continuity in life (Clare 2002, Clare 2003, Steeman *et al.* 2006). Respectively, for the younger study

participants, the diagnosis was a dramatic experience, since they perceived it to be only an older person's condition.

### *Seeking a new equilibrium*

Families' efforts toward seeking equilibrium were ongoing. Since the condition is progressive, these families live in gradually altering life situations and seeking a new balance in life is continuous (Clare 2002). The theory brings forth how each family's illness trajectory has both individual and mutual dimensions. Concurrently with the individual trajectories of managing life with the disorder both personally and as a caregiver, the family as a whole progressed collaboratively on a mutual family trajectory when dealing with the disorder. Thus, the different phases of the illness trajectory and the impact of the disorder were experienced and responded to as a mutual process within the family.

Families started to seek a new equilibrium in their lives by gradually modifying their daily activities and occupations, living conditions, or employment to the needs of the person who was diagnosed or the family as a whole. They aimed to find practical solutions and the means to manage with that altering life. Finding an optimistic viewpoint in the hardships, realizing that life still goes on, and experiencing that everyone can have an influence on family life were elements supporting the families' adjustments to this altering life situation and their acceptance of the disorder as being part of family life. These findings are partially in accordance with the previous research by indicating how individuals develop and use various emotional, practical and social strategies to manage their altering situation (Adams 2006, Beard & Fox 2008, Beard 2004, Beard *et al.* 2009, Bunn *et al.* 2012, Clare 2002, Heimonen 2005, MacQuarrie 2005, Mok *et al.* 2007, Parsons-Suhl *et al.* 2008, Preston *et al.* 2007, Prorok *et al.* 2013, Shim *et al.* 2012, Välimäki *et al.* 2012, Vellone *et al.* 2012). However, unlike the previous studies, this theory clearly brings forth the mutual and collaborative processes taking place within the family when seeking a new balance in life.

In some respect, the findings are in line with the Illness Trajectory framework (Corbin 1998, Corbin & Strauss 1991), which is a conceptual model used to describe chronic conditions' varying and changing course over time. The assumption in the model is that the illness course can be shaped and managed by the individual, the family and the health care practitioners, and that there are many conditions that either facilitate or hinder that management process. However, as memory disorder is a progressive condition, individuals and families'

management centers more around maintaining everyday activities in the early stages and gradually adapting to increasing disability over time than it is related to other management goals that are presented in the Illness Trajectory model (Corbin 1998). Furthermore the substantive theory formulated in this study emphasizes the interpersonal processes in the family more and the family members' collaboration when managing life with the disorder.

The findings for families' experiences when seeking a new equilibrium in life have some similarities to the substantive theories on family survivorship with a parent with cancer (Jussila 2004) and the psychosocial coping of myocardial infarction patients and their spouses (Salminen-Tuomaala 2013). A serious illness is a shock to all family members initiating a process of stabilizing life, and it can have different manifestations depending on how the families face hardships and what is their attitude toward the future (Jussila 2004). Seeking psychosocial balance in a family after a serious incident is a dynamic process where families' experiences of coping with a disease and managing life with it will differ. Seeking a balance contains both emotional and cognitive processes as well as coping with the demands related to the necessary alterations in life-situation, relationships, and their personal roles played. (Salminen-Tuomaala 2013.)

### **6.1.2 Restructure of roles and identity**

Family members' roles shifted gradually toward the caregivers and care receivers' positions. According to the theory, restructuring both roles and identity formed a mutual and interactional adjustment process in the family. For those with the diagnosis, adjusting to their altering self was central in the process of learning to live with a memory disorder, whereas for the family, caregivers' adapting to their new caregiver role became essential, a finding consistent with several other studies (Beard & Fox 2008, Clare *et al.* 2008, Derksen *et al.* 2006, Harman & Clare 2006, Harris & Keady 2004, Harris 2004, Phinney *et al.* 2013, Preston *et al.* 2007, Quinn *et al.* 2008, Sanders & Power 2009, Steeman *et al.* 2006, Steeman *et al.* 2007, Välimäki *et al.* 2012).

It was noticeable that among some families as the condition advanced, the person diagnosed needed more support, concrete help, and surveillance from the family caregiver, and the imbalance between giving and receiving care became much clearer. Further, as the majority of study participants in this study were 65 years of age or younger, thus working aged or just recently retired, it was evident that for them the transition to either care receiver or caregiver contained different

elements than for those families with older participants, a finding supported by the earlier studies (Harris & Keady 2004, Harris & Keady 2009, Harris 2004, Heimonen 2005, Rose *et al.* 2010, van Vliet *et al.* 2010, Ducharme *et al.* 2013).

Study participants balanced their reactions between their distress due to losses and alterations and sustaining hope and optimism, as they reassessed and restructured their roles and identity. Similar findings have been presented earlier (Clare 2002, MacQuarrie 2005, Pearce *et al.* 2002, Steeman *et al.* 2007). People with the memory disorder encountered gradually increasing losses related to their health, functioning, occupation and independence, alterations in daily life, and shifts in their previous roles which affected their sense of self. The greatest demand for people with a memory disorder is coming to terms with their psychological, social and functional losses (Robinson *et al.* 2011).

However, study participants also expressed approving the recognition of their own situation, perseverance to continue being active agents and carrying out meaningful tasks, and optimistic feelings that their life was still worth living. Managing a sense of self is a significant coping demand for individuals (Clare 2003, Harman & Clare 2006, Harris & Keady 2009, Pearce *et al.* 2002, Preston *et al.* 2007, Robinson *et al.* 2005). Sense of identity and personal worth, which are affected by a memory disorder (Beard & Fox 2008, Clare *et al.* 2008, Harman & Clare 2006, Harris & Keady 2004, Harris 2004, Preston *et al.* 2007, Steeman *et al.* 2006, Steeman *et al.* 2007), are crucial factors for these persons' well-being (Kitwood & Bredin 1992, Kitwood 1997). According to the Illness Trajectory model, people do need to make constant identity adjustments during the course of their illness when living with a chronic condition (Corbin & Strauss 1991). People who perceive that they are managing well with their illness feel they have maintained or regained their own sense of self (Daley *et al.* 2013). This current study emphasizes that the person who is diagnosed is acknowledged as a person, can maintain a sense of agency and dignity in life, and experiences other roles than simply being the object of assistance and care, a finding that has also been brought out earlier (Beard *et al.* 2009, Virkola 2014).

Family caregiver distress was related to increased responsibility, difficulties understanding the changes in a close one's behavior, and modifying daily life and activities according to altering needs. Their positive experiences were related to maintaining hope and having the feeling that life is worth living, resilience and perseverance in facing any alterations and difficulties, appreciating togetherness, and being committed to supporting the person diagnosed. In this respect, the results are congruent with previous findings (Black *et al.* 2008, Ivey *et al.* 2013,

Netto *et al.* 2009, Potgieter & Heyns 2006, Pretorius *et al.* 2009, Quinn *et al.* 2008, Robinson *et al.* 2011, Sanders & Power 2009, Shim *et al.* 2013, Vaingankar *et al.* 2013, Vellone *et al.* 2012, Välimäki *et al.* 2012, Williams *et al.* 2014). The results of this study emphasize precisely how family caregivers do have an important role in providing emotional and practical support for the person with memory disorder to thus reinforce that person's sense of identity (Daley *et al.* 2013).

The findings confirm the notion that a close one's chronic and progressive illness affects the whole family system by changing roles, responsibilities, and family functioning (Denham & Looman 2010, Kaakinen *et al.* 2010). Memory disorder impacts family relationships, thus affecting reciprocity, communication, and mutual activities (Ablitt *et al.* 2009). It is common for family caregivers to experience burdens and other negative health outcomes, such as depression at some point during their home care. However, it is notable, that experiencing burdens is a multifaceted phenomenon, and several factors relate to both the person diagnosed and the family caregiver that are associated with any family caregiver negative health outcomes. (Etters *et al.* 2008, Kamiya *et al.* 2014, Kim *et al.* 2012, Papastavrou *et al.* 2007, Schoenmakers *et al.* 2010, Stolt *et al.* 2014). Finding positive meaning through caregiving is a factor that prevents caregivers' feelings of being burdened (Mc Lennon *et al.* 2011).

Although individuals in the current study expressed tensions and uncertainties due to the alterations in daily life, they aimed to find solutions to overcome these challenges and indeed sought new balance within the family. This finding is in line with previous studies showing how families strive to adjust to losses by facing the situation, accepting the changes and focusing on what they have that remains (Robinson *et al.* 2005). Positive family relationships can lessen negative experiences, confirm mutuality in the family and increase the well-being of both the person who has been diagnosed and the family caregiver (Ablitt *et al.* 2009, Carbonneau *et al.* 2010).

### **6.1.3 Mutual processes for managing life with a memory disorder**

The produced substantive theory expresses how family members collaborated to adjust to the changing situation in their families and sought new equilibrium in their altering lives. Managing life with a memory disorder comprised three processes, all of which had both positive and negative elements of hope and distress: 1) acknowledging available qualities and resources; 2) seeking

meaningful social support; and 3) living for today. According to the Illness Trajectory model (Corbin & Strauss 1991), several factors, such as available resources, past experiences, life style, relationships between persons involved in illness management, and nature of the symptoms, will influence the illness management process. These management strategies are not static, but evolve over time (Corbin 1998). Trajectory management refers to the process by which the course of an illness is shaped and managed, for example, by handling crisis and disability and aspiring to maintaining a good quality of life (Corbin & Strauss 1991).

### *Acknowledging available qualities and resources*

One key finding from this study was that people with memory disorder balance between experiencing distress due to losses and aspiring toward a potentially positive existence. This outcome corroborates the remarks of Kitwood & Bredin (1992) and Kitwood (1997) according to which maintaining a sense of agency, retaining the ability to have a control over one's personal life, and being occupied with personally significant actions will support individual personhood and well-being. Previous studies have also noted the importance of experiencing oneself as an autonomous and competent person (Beard & Fox 2008, Clare *et al.* 2008, Harman & Clare 2006, Harris & Keady 2004, Harris 2004, Preston *et al.* 2007, Steeman *et al.* 2006, Steeman *et al.* 2007, Steeman *et al.* 2013), which became further evident in this study. These findings brought out the importance of being valuable for others and giving reciprocal help within the family, as also noted earlier (Mazaheri *et al.* 2013, Mok *et al.* 2007, Steeman *et al.* 2007).

Meaningful activities, including self-care activities, are mechanisms that support management of the disorder (Daley *et al.* 2013). However, people needed gradually to modify their previous activities and functioning as the disorder progressed. This finding is in line with the Illness Trajectory model according to which a person aims to manage the limitations in everyday life activities by altering and adapting those activities to new circumstances (Corbin & Strauss 1991). Similarly as found earlier, the study participants in this study experienced a fear of being a burden to their close relatives when their functioning deteriorates (Clare 2003, Derksen *et al.* 2006, Mazaheri *et al.* 2013, Mok *et al.* 2007, Steeman *et al.* 2013, Vernooij-Dassen *et al.* 2006, Ward-Griffin *et al.* 2006, Werezak & Stewart 2002). The findings of this study indicate that people with younger-onset memory disorder experience greater demands for adapting their previous



activities to their altering situations. The fear of being a burden and the specific experiences of younger people with memory disorder are important aspects to bear in mind when trying to understand and relieve their feelings of distress.

Family caregiver efforts to support the person's participation, activity, and value with understanding and in an encouraging way were the counterbalance for the focus on losses of functioning and did promote a person's self-confidence. The family caregiver role is essential in promoting active agency, social participation and respect of the personhood of those with the diagnosis (Adams 2006, Chung *et al.* 2008, Daly *et al.* 2013, Kindell *et al.* 2014, Phinney *et al.* 2013, Sanders & Power 2009, Taşcı *et al.* 2012, Vikström *et al.* 2008). At the same time, family caregivers have to take into consideration their own needs and the whole family's needs and its well-being (Bakker *et al.* 2010, Daly *et al.* 2013, Heimonen 2005). Families' efforts to seek a new balance in life call for acting to uphold their previous activities and modify them as necessary. In this respect, the results here are consistent with the notion that living with a memory disorder is a trajectory of maintaining continuity and facing losses (Gillies 2012). Altogether, these results provide new understanding of the ways families aim to hold on to life by clearly acknowledging available resources and qualities in their altering situations.

### *Seeking meaningful social support*

Being socially connected and having meaningful social support was important for both for the person diagnosed and the family caregiver, although it had different meanings for each of them. The findings indicate that emotional and practical support from their closest social network, such as spouses, children, and grandchildren, are significant forms of social support for those with the disorder. For the family caregivers, it was also important to get social support from others, such as peers, neighbors, and professionals. The previous research supports these findings (Frazer *et al.* 2012, Heimonen 2005, Phinney *et al.* 2013, Pison-Young *et al.* 2012, Preston *et al.* 2007, Steeman *et al.* 2006, Wolverson *et al.* 2010).

The results here stress the importance of close relationships. Relying on close relatives, mutual sharing, and feelings of togetherness relieves a person's negative feelings, such as sorrow and shame, and provides a possibility to grieve with a safe companion. Furthermore, these feelings of shame and social stigma were not present in the relationship with the closest ones; instead, at their best, close relationships promoted feelings of trust and safety for those with the diagnosis.

Better emotional well-being of the caregiver and care-receiver, better adjustment to the alterations, and more positive experiences of living with the memory disorder can be achieved through the good quality of the daily relationship within a family (Ablitt *et al.* 2009, Braun *et al.* 2009, Carbonneau *et al.* 2010). Hellström *et al.* (2005, 2007) in their studies emphasized the meaning of couplehood as a process where spouses work together and strive to sustain the quality of life when living with memory disorder. Couples aim to overcome these challenges together by working through difficulties, doing things together, and being there for each other, a choice that preserves their couplehood, mutual sharing, and feelings of togetherness (Davies 2011, Graham & Bassett 2006, Hellström *et al.* 2007).

Interestingly, the results of this study indicate also that for some people with a memory disorder peer support or support from a wider social network was not regarded as valuable as the family caregivers. It seemed they tried to normalize their image of self and did not want to be acknowledged by their condition, as noted in earlier studies (Beard & Fox 2008, Beard *et al.* 2009, McRae 2010). Memory disorder has a negative and stigmatized image that too often influences our views of people living with it (Alzheimer's Disease International 2012, Burgener & Berger 2008, Innes 2009). It may be that by keeping the disorder a personal and a family matter, many people tried to maintain that positive image of self. However, it is also important that there remain possibilities for people with memory disorder to talk about and make sense of their experiences and feelings (Pearce *et al.* 2002), whether with close relatives, peers, professionals, or other people they trust.

Earlier research has demonstrated that perceived social support from immediate family, friends, and professionals promotes better coping with the grief following a loss, traumatic incident, or a significant bereavement related to health and illnesses (Benkel *et al.* 2009, Calvete & de Arroyabe 2012, Kaunonen 2000, Kaunonen *et al.* 1999, Sanders *et al.* 2008). Organized support groups have been found to be effective for family caregivers' well-being and coping skills (Chien *et al.* 2011, Gaugler *et al.* 2011, Sørensen *et al.* 2008a, Wang *et al.* 2012). Although peer support for people with memory disorder is not always regarded as unambiguously helpful (Gaugler *et al.* 2011), it does offer benefits if it provides a context in which to come to terms with the disorder and find ways to manage it in everyday life (Clare *et al.* 2008, Sørensen *et al.* 2008a, Willis *et al.* 2009).

The results show how memory disorder has an influence on individuals and families' social relations due to a person's declining functioning and family caregivers' increased responsibilities. In this respect, the results of this study

corroborate the notions which indicate that being safely attached to other people, having access to reciprocal social relations, and belonging to a social group are all significant for a person with memory disorder. Indeed, they are crucial factors that support the well-being and personhood of the person with the memory disorder (Kitwood & Bredin 1992, Kitwood 1997). The continuation of existing social networks and their roles, being engaged with others and society, and making sense of the illness are all positive factors that support positive management of the disorder (Daley *et al.* 2013).

### *Living for today*

A central notion in this study was that the efforts made to live in the present, focusing on the existing resources and the good things in life and appreciating common everyday life helped to manage uncertainties and fear of future losses for both the people diagnosed and the family caregivers. This finding corroborates the earlier studies on managing life with memory disorder that found that by living one day at a time and focusing on the positive in life were excellent skills (Beard *et al.* 2009, Bunn *et al.* 2012, de Witt *et al.* 2010, MacRae 2010, Pretorius *et al.* 2009, Quinn *et al.* 2008, Sanders & Corley 2003, Shim *et al.* 2013). Families needed to confront the losses and alterations, accept their changed life story and welcome their new script for a life containing uncertainties. Families showed perseverance in their resilient attitudes and their orientation toward not giving up. They also aimed to find an alternative, optimistic interpretation of the difficulties and alterations in life, and these also helped them to accept their situation. Similar findings have been brought out in earlier studies (Clare 2002, Clare 2003, Heimonen 2005, Pretorius *et al.* 2009, Steeman *et al.* 2007, Williams *et al.* 2014). Remaining positive and focusing on what could still be done rather than what has been lost is an important strategy for managing this illness (Beard & Fox 2008, Preston *et al.* 2007). Steeman *et al.* (2013) also pointed out that as the condition progresses, it becomes even more important to acknowledge who the person is rather than what he or she is able to do.

It was apparent that for these families, managing an altering and uncertain life meant balancing with hope and distress. This finding is in accordance with the notion that families with chronic illness oscillate between hope and despair (Chesla 2005). Retaining a sense of hope, having confidence that the future will not be frightening despite its alterations, and experiencing comfort during troubled times are important elements for the well-being and personhood of the

person with the memory disorder (Kitwood & Bredin 1992, Kitwood 1997). This study indicated similar aspects of hope for family caregivers. Individuals and families' hopes were related to maintaining both their important relationships and current functioning of loved ones as long as possible and also sustaining an optimistic attitude by focusing on abilities and competencies. These are findings partly supported by earlier studies (Heimonen 2005, Wolverson *et al.* 2010, Cotter 2009). Importantly, the study participants' hopes represented definite positive elements and possibilities for an uncertain life (Duggleby *et al.* 2010).

#### **6.1.4 Substantive theory of managing life with a memory disorder and the core category of 'Accepting memory disorder as part of family life'**

The substantive theory of managing life with memory disorder describes the alterations that families face and the means they use to manage their altering life during the first years dealing with a memory disorder. The substantive theory formulated in this study is inductively produced descriptive situation-specific theory, which describes the phenomena of interest and names the concepts and their properties but do not explain the interrelationships between them (Im 2005, Lauri & Kyngäs 2005, McEwen 2007c).

The theory comprises a core category of 'Accepting memory disorder as part of family life' and categories with their own subcategories, i.e., the concepts that illustrate the 1) transitional phases that families encounter before and after the confirmation of the diagnosis; 2) the restructuring of family members' roles and identities due to alterations in family life; and 3) family members' mutual processes for managing life with a memory disorder. Managing life with a memory disorder produces mutual processes in a family that contains both positive and negative factors of hope and distress. The theory highlights the mutual and shared processes within the family and those means that family members will use to manage their altering life experience as they deal with a progressive memory disorder. This finding is a point that has seldom been investigated in earlier studies. In addition to mutual familial processes, the theory provides better understanding of the dynamics of hope and distress within the family context.

Accepting memory disorder as part of a family's life stands for optimistic and positive adjustments to the alterations occurring within that family. It refers to a process wherein family members collaborate to respond to ongoing changes

without denying or giving up, but instead by confronting the reality and aiming to manage it by using the best of their resources. Indeed, this part of the theory offers a unique insight into the experiences of families who are confronted with a life-shattering event.

Although a diagnosis of memory disorder is a crisis, it is not necessarily the end of a personal and familial biography. It can be experienced as a new beginning and reframed as a manageable disability (Beard et al. 2009). As Heimonen (2005) points out, adapting to the altering of a life situation with the memory disorder can be seen as a possibility to learn new things in and about life. Based on the results of the current study, these new things can relate to a closer relationship with one's spouse and others in the immediate network. Furthermore, these new things can become the family's means to survive in troubled times, learn problem-solving skills in everyday life, find resilience and perseverance when facing difficulties, retain active agency, recognize those elements that bring enjoyment and a joy of life, handle feelings of distress, sorrow, and fear, and adopt a more optimistic and approving attitude toward the self, others, and life overall.

## **6.2 Trustworthiness of the theory**

Trustworthiness of the theory was intended to be ensured by following the standard criteria for qualitative studies: Credibility, dependability, transferability, confirmability, and authenticity (Graneheim & Lundman 2004, Polit & Beck 2012) and the quality conditions for grounded theory study (Corbin & Strauss 2008).

The truth of the data and their interpretations, i.e., *credibility* (Graneheim & Lundman 2004, Polit & Beck 2012) was strengthened by obtaining as rich a variation of data as possible according to a designed study plan and through the researcher's thorough preparation. The researcher prepared for the study procedure before entering the field for the data collection. The same researcher conducted the interviews and analyzed the data that supported the credibility of the study. To avoid bias, the inclusion criteria for recruiting the study participants from the memory clinic were broad. Families who met the criteria were offered the possibility to participate in the study in sequence, and the majority of those who were asked agreed to participate. However, it is possible that the sample was slightly weighted to well-managed families. Despite the small sample size, the

study participants did have diverse backgrounds and experiences, thereby forming a heterogeneous group of informants.

A rich and in-depth understanding of the phenomenon in focus was accomplished with a longitudinal research design and repeated interviews using unstructured observations. Joint interviews with family caregivers were two-fold, and on the other hand, they also promoted safety for the interviewees with memory disorder when the family caregiver promoted emotional support or acted as an aide-memoire. On the other hand, the presence of the family caregiver may have interfered with the individuals' voices being heard whenever verbalizing was difficult for the person with memory disorder or when the family caregiver wanted to vent his or her feelings about burden. However, joint interviewing also had a possibility of producing a different kind of understanding of the mutual meanings of living with memory disorder (Davies 2011).

Interviewing sensitive subject with vulnerable study participants required both a confidential and an approving atmosphere. There is a possibility that study participants did not reveal difficult issues in their research interviews. Therefore, additional data collection methods, such as diaries or visual research methods such as photovoice (Bartlett 2012, Genoe & Dupuis 2013, Välimäki *et al.* 2007), along with the interviews and observations could have been useful. Still, it was the researcher's impression that the interviews were confidential conversations wherein the study participants' experiences were sufficiently revealed and a shared construction of each family's life situation was delivered to the researcher.

Application of theoretical sampling could also be criticized. Ideally, in grounded theory, the researcher should seek new participants based on the analysis process (Corbin & Strauss 2008). However, for practical reasons, the suitable place for recruitment in this study was determined beforehand, since it was possible to reach families from the memory clinic after disclosure of the diagnosis. In this study, the theoretical sampling was based on concepts, not people, and gathering new data was based on what was discovered during previous data analyses (Corbin & Strauss 2008). The data analysis and interpretation required going back and forth between the data and the generated categories and the theoretical memos that supported the interpretation of the data. Prolonged data collection and analysis ensured saturation of the categories and thus increased the overall credibility of the study.

The stability of data over time and conditions, i.e., *dependability* (Graneheim & Lundman 2004, Polit & Beck 2012) was ensured by conducting the interviews in a cyclical process where the researcher was able to collect data in a consistent

manner. The broad themes guided the first interviews with all the families, while following interviews were based on what was found in the earlier interviews both within the same family and between different families. The researcher kept a research diary, which helped to gather her thoughts and increased the awareness of the data collection and analysis process. The use of computer-assisted data analysis software provided a good means to manage the data and analysis process and increased the trustworthiness of the data handling. Furthermore, the analysis process and its results were discussed with the supervisors (co-writers of the original Articles I, II and III) during the course of the study.

The extent to which the findings from this study are applicable to other settings or groups, i.e., *transferability* (Graneheim & Lundman 2004, Polit & Beck 2012) can be assessed by the reader. Transferability can be evaluated based on the descriptions of conducting the study. The context and research process are described as clearly as possible. Furthermore, the results with representative citations are provided for readers to assess the full applicability of the findings.

The objectivity of the results, i.e., *confirmability* (Polit & Beck 2012) can be assessed in terms of how well the findings reflect the study participants' true experiences, not the bias and preconceptions of the researcher. Such confirmability may have been threatened, as only a single researcher conducted the interviews and the analysis. This issue was compensated for by the researcher in the following ways: Striving to be conscious of her preconceptions before starting the data collection and during the analysis process by reflecting on thoughts and ideas delivered to the memos and research diary, having reflective discussions with supervisors who are experts in the field of the study subject, and keeping a clear and controlled record of the original data, the coding process and any memos in an electronic format in the data analysis software. The use of an external audit to evaluate the accuracy of the analysis process and its results however could have further improved confirmability.

The extent to which the theory succeeds and depicts a range of different realities of the study participants, i.e., *authenticity* (Polit & Beck 2012) can also be assessed by the reader. The research process was conducted inductively in order to obtain a truthful and sensitive understanding of the lives of the study participants, while a broad range of authentic citations were selected for the readers to give them further comprehension of the participants' experiences.

The following conditions (Corbin & Strauss 2008) were implemented to obtain a profound understanding of study participants' experiences and foster the overall quality of the study: Grounded theory was selected as a research method

based on the purpose of the study and carried out with a consistent procedure; the researcher aimed to have high self-awareness of possible biases, assumptions, and interpretations throughout the study and prepared herself in advance for the methodological and ethical questions; further the researcher aimed to preserve situational sensitivity, personal responsiveness and creativity when collecting and analyzing the data. According to Cowdell (2006) the researcher's skill, expertise, and manner are central to the credibility of the study.

Further still, the produced theory and its usefulness can be evaluated for several factors (Corbin & Strauss 2008). The research process and the results are described as thoroughly as possible, so the readers can assess following questions: How well the produced theory represents the real world and does it demonstrate the variation of human life?; What is the structure of the theory, and how the concepts relate to each other?; Is the theory logical, and are the findings presented creatively and produced inductively based on the participants' experiences, not the researcher's preconceptions; and Can the theory be used to develop actual useful practice?

### **6.3 Implications**

Use of the research findings can change professionals' way of thinking and increase their awareness of both their patients' and their families' experiences. The research knowledge can also be implemented to change actual protocols of practice and create changes within organizations. (National Collaborating Centre for Methods and Tools 2011, Stetler 2001). A reciprocal relationship with nursing theory and practice can indeed be pivotal (McEwen 2007a). Nursing practice is based on diverse patterns of knowing, and empirical research provides a sound basis for theory-guided evidence-based practice (Fawcett *et al.* 2001, McEwen 2007b). The findings of this study confirm and supplement the current knowledge base in nursing science for families' experiences and the means they use to manage life after the diagnosis of a progressive memory disorder. The findings can be utilized by professionals working with individuals and families living with early-stage memory disorder. This study can also be utilized for nursing education, especially when supporting students to apply research-based knowledge to individualized care for individuals and families experiencing memory disorder diagnoses, and promoting student skills for developing research-based practices (Christie *et al.* 2012). The implications of these findings for the



care of people with memory disorder and their family caregivers and also future research in nursing science are discussed further in the following chapters.

### **6.3.1 Implications for care of those with a memory disorder and their family caregivers**

Living with memory disorder is a family matter that affects the whole family's health and well-being. Members of the family must collaborate to manage these life alterations. Therefore, family-centered interventions that support family adjustment are necessary in social and health care services. The family nursing approach can provide a necessary framework for the care and rehabilitation of patients and their immediate family who are living with memory disorder. The knowledge of family structure, functioning, family dynamics, resources, and coping strategies are necessary when carrying out individualized family interventions so as to foster positive family resilience in times of crisis (Kaakinen *et al.* 2010).

These findings indicate that families' needs are unique and constantly changing due to the progressive nature of the memory loss condition. Therefore, individualized care and rehabilitation interventions for families as well as continuous appraisal of these families' situations to modify services according to ongoing changing needs are necessary. Nursing care that is tailored to the needs of patients will have positive effects on patient outcomes (Suhonen *et al.* 2005b, Suhonen *et al.* 2008b). Further, interventions should be age specific and take into account the different needs of families experiencing early-onset and late-onset memory disorder (Beattie *et al.* 2004, Harris & Keady 2004, Harris 2004, Rose *et al.* 2010). However, it should be kept in mind that services should be provided according to the needs of the patients and their families rather than based on age categories, since there are common elements for the needs of families dealing with early-onset and late-onset memory disorder (Beattie *et al.* 2002).

The findings of this study indicate that tailored psychosocial support for both the person with a newly diagnosed memory disorder and those in the immediate family should focus on how to adjust to new roles and preserve the positive sense of self, how to identify resources, qualities and possibilities in everyday life, how to have opportunities for social support and social participation, and maintain hope by finding elements of meaningful life. The implementation of family-centered care and rehabilitation plans should be carried out in a coordinated way by a professional, e.g., a case manager, memory coordinator, or family care

coordinator, who works in cooperation with the patients and their families and tailors services according to their needs (Eloniemi-Sulkava *et al.* 2001, Eloniemi-Sulkava *et al.* 2009, Ministry of Social Affairs and Health 2013a, Pierce 2010, Suhonen *et al.* 2008a). These coordinated, flexible and individualized services for families are cost effective and they may also delay the long-term institutionalization of the patient (Eloniemi-Sulkava *et al.* 2001, Eloniemi-Sulkava *et al.* 2009).

Families can face hardships due to the progressive nature of a memory disorder, but they also can experience positive elements in their lives and have diverse resources to utilize when striving to the health and well-being of these individuals and their families. The empowering approach that supports and strengthens these individuals and their families' unique resources helps both to find a new equilibrium in the altering life and fosters hope. Hope is essential when providing social and health care services, so it is necessary to develop interventions that support both individuals and families in order to manage and maintain optimal well-being while living with the disorder. Therefore, multi-component, tailored interventions for both patients and their informal caregivers should include education, psychological interventions, practical support, and counseling on the care and coping with the disorder (Vernooij-Dassen & Olde Rikkert 2004).

Self-management has become the dominant mode in health care today (Hallberg 2009). It has been used as an approach in the context of chronic diseases, such as coping with mental illness (Kemp 2011, Mueser *et al.* 2002), but it has also begun to emerge in the care of people with memory disorder (Daley *et al.* 2013, Mountain 2006, Vernooij-Dassen & Olde Rikkert 2004). The premises for self-management are that both patients and their families are empowered to become active participants in this care, and they can be supported to learn how to manage the condition (Kemp 2011, Mountain 2006, Mueser *et al.* 2002, Vernooij-Dassen & Olde Rikkert 2004). This view is consistent with the recovery approach, which emphasizes the following: Personal agency; maintaining a positive sense of identity, resourcefulness and strengths; hope and optimism, having connection with others, and being empowered to manage and live a satisfying life (Adams 2010, Daley *et al.* 2013, Gavan 2011, Irving & Lakeman 2010, Martin 2009). Recovery means a process that promotes personal adaptation, hope-inspiring relationships, and a person's inclusion, if not cure, improvement or absence of the disorder (Adams 2010, Irving & Lakeman 2010, Martin 2009). The recovery approach provides an optimistic focus for empowering individuals

to achieve optimal well-being and live a meaningful life even with a disorder (Gavan 2011). It has been proposed that this recovery model suits the diagnostic phase best and the early-stages of memory disorder when people can still make decisions concerning their lives (Adams 2010, Irving & Lakeman 2010, Martin 2009). Its broader applicability to the care and rehabilitation of those with memory disorder should also be evaluated.

The results of this study confirm that family caregivers have an important role to play to support the person who has been diagnosed. However, family caregiving also poses a threat to the caregivers' overall health and quality of life (Välimäki 2012, Välimäki *et al.* 2012). Therefore, it is important to pay attention to their well-being and provide appropriate informational, practical, financial and psychosocial support to maintain the quality of life of both the care recipient and the caregiver (World Health Organization 2012). Well supported informal caregiving reduces the risk of an overwhelming family caregivers burden, and it calls for tailored, sufficient, flexible and timely services and support to secure family caregivers' and care receivers' well-being and ability to live at home (Ablitt *et al.* 2009, Eters *et al.* 2008, Ministry of Social Affairs and Health 2014). The transition to long-term care can be delayed by supporting the patient's ability to function, and securing the well-being of family members who are caregivers by delivering both efficient and coordinated services (Eloniemi-Sulkava *et al.* 2001, Eloniemi-Sulkava *et al.* 2009, Ministry of Social Affairs and Health 2013a).

In summary multi-component, coordinated, and individualized family-centered care and rehabilitation interventions can strengthen both individuals' and families' resources, foster hope, and empower both to achieve optimal well-being and live a meaningful life with a diagnosis of memory disorder. These elements are needed especially after a confirmation of a diagnosis in the early phases of memory disorder.

### **6.3.2 Implications for future research**

As the theory is a constantly evolving process, the generated substantive theory should be refined further from a descriptive theory to an explanatory theory. Testing and developing the produced substantive theory requires defining and operationalizing both its concepts and statements further and setting forth new hypotheses for testing. (Lauri & Kyngäs 2005, McEwen 2007c). There is also a possibility to refine the produced substantive theory further to produce a more generalized formal theory for managing life with chronic or progressive diseases.

This focus would require further research and can be done by selecting previous studies concerned with illness-related management among diverse groups for systematic comparisons and also seeking out the variations in other situations and groups for empirical research, for example, different family types living with memory disorder, families with younger-onset and late-onset memory disorder, families with teenage children, and even other types of medical conditions and families living with life-altering situations (Corbin & Strauss 2008, Kearney 2007). Comparing the data across different contexts provides a possibility of raising the concept to a more abstract level and applying the theory in broader terms (Corbin & Strauss 2008). In nursing science, there is an ongoing need to carry out research that better informs practice (Hallberg 2009). The findings of this study can inform the further research on developing and testing nursing interventions that support individuals and families who are managing an altering life and designing a practical tool to assess that management of a memory disorder.

More research is needed on the interpersonal processes and family dynamics in families living with memory disorder. Further research on the similarities and differences of the adjustment process between families with early-onset and late-onset memory disorder is also essential. Moreover, such future research could widen the focus of interest to other close relatives and people in the immediate network, not just the person diagnosed and the main family caregiver. Further research concerning managing life with a memory disorder could focus on different family types, such as culturally diverse families, blended families, and late-life marriages or relationships. It is also important to study how people who live alone with a memory disorder manage their lives with the altering situations, since they will face different demands and possibilities than those living with their next of kin (De Witt *et al.* 2009, de Witt *et al.* 2010, Duane *et al.* 2013, Virkola 2014).

Research concerning the diagnostic phase and family management strategies and the need for support is necessary, since confirmation of a memory loss diagnosis is a turning point in the family life course. This study focused on families' experiences during the first years after the diagnosis. It is also significant to investigate the family processes during the later stages when the disorder progresses and families face new alterations, such as a shift to respite care or long-term care. Longitudinal research design could achieve those changes that families face during the course of time. It would also be valuable to investigate the factors that foster individuals' and families' hopes when living

with memory disorder. That would make it possible to develop empowering interventions to support families and help them achieve optimal health and well-being in their lives. There is also a need to construct new, innovative, and ethically sound data collection methods (Cowdell 2006) to obtain the different viewpoints of those with the diagnosis, especially in the more advantaged stages when the ability to express themselves verbally has declined.



## 7 Conclusions

Based on the results of this study, the following conclusions are offered:

1. Families live through different phases in their illness trajectories before the diagnosis of a memory disorder is confirmed. Diagnosis forms a turning point in the family life course and leads family members to seek a new equilibrium.
2. Diagnosis of a memory disorder affects the whole family by changing family members' roles and identities. Restructuring roles and identities is mutual and interactional adjustment process in a family.
3. Family members must collaborate to manage such life alterations. Mutual processes for managing life with a memory disorder comprise the following specific factors: acknowledging available qualities and resources, seeking meaningful social support, and living for today.
4. Managing life with a memory disorder includes both positive and negative elements of both hope and distress. Accepting memory disorder as part of a family's life can lead to optimistic and positive adjustment to the alterations occurring within that family.
5. Conducting ethically sound research with vulnerable study participants requires careful preparation and planning as well as continuous reflection and assessment of both actions and decisions in all phases of that study. Despite ethical and methodological challenges when conducting research with people with a memory disorder and their close relatives, it is vital that they are included in the research. Innovative and ethically sound data collection methods to attain this goal should be developed.
6. Multi-component, coordinated, and individualized family-centered care and rehabilitation interventions that strengthen the individuals' and the families' resources, foster hope and empower both to achieve optimal health and well-being and live a meaningful life with the memory disorder are needed in the early phases of this illness trajectory.
7. Further research is needed on the similarities and differences in family processes among diverse families and those factors that foster hope when families are living with a memory disorder.





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# Appendices

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## Appendix 1 Characteristics of the studies on living with memory disorder from both the perspectives of both the patients and the family caregivers

Author(s), year and country	Study participants / material	Data collection method	Data analysis method
Adams 2006, U.S.	20 spouse and daughter caregivers aged 45–82 years	Semi-structured individual interviews	Phenomenology and grounded theory approach
Aubeeluck et al. 2012, UK.	47 family caregivers of persons with Huntington's disease	Semi-structured focus-group discussions	Interpretative phenomenological analysis
Bakker et al. 2010, Netherlands	Case study of one wife caregiver	Semi-structured interviews	Inductive content analysis
Beard 2004, U.S.	13 patients	Participant observation, in-depth interviews and focus groups	Grounded theory approach
Beard et al. 2009, U.S.	27 patients	Internet-based survey with open-ended questions	Grounded theory approach
Beard & Fox 2008, U.S.	40 patients (mean age 71 years)	Focus groups and individual interviews	Grounded theory approach
Beattie et al. 2004, UK	14 patients aged 41–66 years	Semi-structured in-depth interviews	Grounded theory approach
Black et al. 2008, U.S.	Four male spouse caregivers aged 80 and over	Ethnographic interviews and informal conversation	Qualitative data analysis
Bunn et al. 2012, UK	Systematic review of qualitative studies	Databases: PubMed, PsychINFO, Embase, CINAHL, and the British Nursing Index	Thematic synthesis
Carpentier et al. 2010, Canada	60 family caregivers	Interviews	Content analysis, social network analysis and narrative analysis

Author(s), year and country	Study participants / material	Data collection method	Data analysis method
Che et al. 2006, Taiwan	Nine female family caregivers aged 33–50 years	In-depth interviews	Grounded theory approach
Chrisp et al. 2012, UK	Case study data of 20 family caregivers	Documentation collected during service evaluation and interviews	Qualitative thematic analysis
Chung et al. 2008, UK	15 family caregivers aged 50–80 years	In-depth interviews	Grounded theory approach
Clare 2002, UK	12 patients aged 57–83 and their spouse caregivers aged 52–78	Individual in-depth interviews	Interpretative phenomenological analysis
Clare 2003, UK	12 patients aged 57–83 and their spouse caregivers aged 52–78	Individual in-depth interviews	Interpretative phenomenological analysis
Clare et al. 2008, UK	Seven patients aged 48–66 years	E-mail interviews	Interpretative phenomenological analysis
Daly et al. 2013, Ireland	19 informal caregivers and 10 professionals	In-depth interviews	Grounded theory approach
Davies et al. 2010, U.S.	23 spouse caregivers (mean age 75 years)	Focus groups	Thematic analysis
De Witt et al. 2010, Canada	Eight female patients aged 58–87 years	Interviews	Interpretative phenomenological analysis
Derksen et al. 2006, Netherlands	18 couples with patients (mean age 71 years) and their partners	Semi-structured individual interviews	Grounded theory approach
Ducharme et al. 2013, Canada and France	12 spouse caregivers (mean age 55 years)	Semi-structured interviews	Qualitative data analysis
Edwards 2014, U.S.	10 adult child caregivers	Face-to-face and telephone interviews	Phenomenological approach
Eriksson et al. 2013, Sweden	12 female caregivers aged 66–80 years	Series of interviews	Qualitative feminist approach
Ford et al. 2012, U.S.	Case study with three wife caregivers	In-depth interviews and questionnaire	Phenomenological approach
Frazier et al. 2012, UK	Eight female patients aged 75–95 years	Interviews	Interpretative phenomenological analysis

Author(s), year and country	Study participants / material	Data collection method	Data analysis method
Galvin et al. 2005, UK	Case study of one male caregiver	Series of interviews	Hermeneutic-phenomenological method
Gillies 2012, UK	20 family caregivers	Individual interviews or interviews with the patient present	Grounded theory approach
Gilmour & Huntington 2005, New Zealand	Nine patients aged 56–79 years	Semi-structured interviews	Thematic analysis
Graham & Basset 2006, Canada	88 patients (mean age 76 years) and their family caregivers (mean age 61 years)	Interviews and ethnographic notes	Qualitative data analysis
Harman & Clare 2006, UK	Nine patients aged 58–76 years	Semi-structured interviews	Interpretative phenomenological analysis
Harris 2004, U.S.	23 patients aged 43–68 years	Focus groups, face-to-face interviews and on-line interviews	Grounded theory approach
Harris & Keady 2004, UK and U.S.	23 patients aged 43–68 years and 15 family caregivers aged 21–64 years	Focus groups, face-to-face interviews and on-line interviews	Grounded theory approach
Harris & Keady 2009, UK and U.S.	23 patients aged 43–68 years and 15 family caregivers aged 21–64 years	Focus groups, face-to-face interviews and on-line interviews	Grounded theory approach
Hayes et al. 2009, U.S.	28 spousal caregivers	In-depth interviews	Grounded theory approach
Heimonen 2006, Finland	12 patients aged 52–64 years and 10 spouse caregivers aged 50–67 years	Individual interviews	Qualitative data analysis
Hughes et al 2009, U.S.	17 caregivers aged 42–80 years	Semi-structured interviews	Grounded theory approach
Huilko 2009, Canada	Primary research participants: eight patients aged 74–87 years. In addition: significant others, and others in the immediate network	Interviews, observations, and focus groups	Grounded theory approach
Ivey et al. 2013, U.S.	75 family caregivers from two ethnic groups	Focus groups	Thematic analysis

Author(s), year and country	Study participants / material	Data collection method	Data analysis method
Johannessen & Möller 2013, Norway	20 patients aged 54–67 years	Interviews	Grounded theory approach
Kamiya et al. 2014, Japan	1127 patients and their caregivers	Several assessment batteries (MMSE, GDS, BI, LI, DBD, ZBI) to evaluate disability, mood and cognitive function of the patients and burden of caregivers.	Statistical analysis using SPSS
Keady et al. 2007, UK	Case study of a person with Alzheimer's disease and a clinical nurse specialist	Co-Constructed Inquiry	Development of a personal theory
Kindell et al. 2014, UK	Case study of wife and son caregivers	Semi-structured interviews	Narrative analysis
Koehn et al. 2012, Canada	10 patients aged 72–86 years and their family caregivers	Individual semi-structured interviews	Qualitative analysis with a critical constructionist and intersectional framework
Langdon et al. 2007, UK	12 patients aged 66–87	Semi-structured interviews	Interpretative phenomenological analysis
Lawrence et al. 2011, UK	30 patients aged 65–96 years	In-depth interviews	Grounded theory approach
Lee & Smith 2012, U.S.	Four wife caregivers (mean age 72 years) and four female adult child caregivers (mean age 60 years)	Semi-structured in-depth interviews	Qualitative content analysis
Leung et al. 2011, Canada	Six patients aged 55 years and older and seven family caregivers	Individual and joint semi-structured interviews	Inductive, thematic analysis
Lin et al. 2012, Taiwan and UK	Six spouse caregivers aged 64–72 years	Semi-structured in-depth interviews	Grounded theory approach
Lockeridge & Simpson 2012, UK	Six family caregivers aged 52–70 years	Semi-structured interviews	Interpretative phenomenological analysis
MacQuarrie 2005, Canada	13 patients aged 60–89 years	Interviews	Constant comparative method

Author(s), year and country	Study participants / material	Data collection method	Data analysis method
MacRae 2010, Canada	Nine patients aged 60–85 years	Semi-structured in-depth interviews	Qualitative data analysis
Mazaheri et al. 2013, Sweden and Iran	15 patients aged 60–87 years	Semi-structured interviews	Qualitative content analysis
McCleary et al. 2012, Canada	Six patients aged 74–84 years, and eight family caregivers	Semi-structured in-depth individual or joint interviews	Qualitative content analysis
McLennon et al. 2011, U.S.	84 spouse caregivers aged 49–96	Several assessment batteries (The Cognitive Status Scale, FMTCG Scale, ZBI and SF-36) to evaluate cognitive status of care recipient, positive aspects of caregiving, and overall health status and burden of caregivers.	Statistical analysis using SPSS
Meuser & Marwit 2001, U.S.	42 spouse caregivers (mean age 72 years) and 45 adult child caregivers (mean age 52 years)	Questionnaire and semi-structured focus group interviews	Qualitative data analysis
Mok et al. 2007, China	15 patients aged 56–80 years	In-depth interviews	Phenomenological approach informed by Colaizzi
Morgan et al. 2014, Canada and UK	46 family caregivers	Semi-structured individual or joint interviews with family members	Grounded theory approach
Navab et al. 2013, Iran	10 family caregivers aged 25–67 years	Semi-structured interviews	Hermeneutic phenomenological approach
Netto et al. 2009, Singapore	12 family caregivers aged 32–72 years	Semi-structured in-depth interviews	Grounded theory approach
Neufeld et al. 2007, Canada	15 women caregivers of persons with memory disorder. In addition women caregiver groups for other contexts.	Series of in-depth interviews	Thematic data analysis

Author(s), year and country	Study participants / material	Data collection method	Data analysis method
Neufeld & Harrison 2003, Canada	Eight women caregivers aged 37–70 years	In-depth interviews	Thematic content analysis
Neufeld & Kushner 2009, Canada	34 male family caregivers, five assisting caregivers and 15 professionals	In-depth interviews, focus groups and diaries	Thematic analysis
Nichols et al. 2013, Canada and U.S.	14 teenaged children aged 11–18	Semi-structured interviews in focus groups	Thematic analysis
O'Connor et al. 2010, Canada	Case study: one patient and her partner	In-depth personal and family interviews and video-taped participant observation	Narrative and discourse analyses
O'Dwyer et al. 2013, Australia	Nine family caregivers aged 25–82 years	Semi-structured interviews	Thematic analysis
O'Shaughnessy et al. 2010, UK	Seven spouse caregivers aged 59–86 years	Semi-structured interviews	Interpretative phenomenological analysis
Parsons-Suhl et al. 2008, Canada and U.S.	12 patients aged 59–83 years	Unstructured interviews	Textual analysis informed by Heideggerian hermeneutical phenomenological research method
Pearce et al. 2002, UK	20 patients with Alzheimer's disease aged 63–84 years and their wives	Semi-structured individual interviews	Interpretative phenomenological analysis
Phinney et al. 2013, Canada	Two families: men (n=2) with their family caregivers (n=5)	Individual and joint interviews	Interpretative phenomenological analysis
Pipon-Young et al. 2012, UK	Eight patients aged 60–67 years	Interviews and action research groups	Thematic analysis
Potgieter & Heyns 2006, South Africa	Eight female spouse caregivers aged 37–71 years	Support group discussions, individual interviews, personal diaries and questionnaire	Qualitative data analysis

Author(s), year and country	Study participants / material	Data collection method	Data analysis method
Preston et al. 2007, UK	12 patients aged 58–81 years	Semi-structured interviews	Interpretative phenomenological analysis
Pretorius et al. 2009, South-Africa	10 male spouse caregivers aged 61–86 years	Semi-structured in-depth interviews	Qualitative data analysis
Prorok et al. 2013, Canada	Systematic review of qualitative studies	Databases: MEDLINE, Embase, PsycINFO and CINAHL	Meta-ethnographic analysis
Purves & Phinney 2012, Canada	Two families with patients (n=2) and close relatives (n=9)	Semi-structured interviews, recorded everyday conversations and participant observation	Thematic analysis using constant comparative analysis, interactional sociolinguistics and conversation analysis
Quinn et al. 2008, UK and New Zealand	34 spouse/partner caregivers aged 52–80 years	Semi-structured interviews	Interpretative phenomenological analysis
Robinson et al. 2011, UK	Systematic review	Databases: Medline, CINAHL, Web of Science, EMBASE and Sociological Abstracts	Narrative review
Rose et al. 2010, U.S.	Four patients	Case studies design	Content analysis
Sabat 2011, U.S.	Case study of one wife caregiver	Longitudinal case study with e-mail communication	Case study analysis
Samsi & Manthorpe 2013, UK	12 couples with patients and caregivers aged 49–92 years	Series of interviews	Thematic analysis according to phenomenological approach
Samsi et al. 2014, UK	27 patients aged 65 years and older and 26 carers	In-depth interviews	Grounded theory approach
Sanders & Corley 2003, U.S.	253 caregivers	Questionnaire with open-ended questions	Thematic analysis
Sanders & Power 2009, U.S.	17 male spouse caregivers aged 66–85 years	Semi-structured interviews	Phenomenological approach



Author(s), year and country	Study participants / material	Data collection method	Data analysis method
Shaji et al. 2003, India and UK	17 family caregivers	Interviews	Constant comparison analysis
Sherman 2012, U.S.	60 wife caregivers aged 45–87 years	Telephone interviews	Interpretive description approach
Sherman & Boss 2007, U.S.	Nine wife caregivers aged 51–79 years	In-depth interviews	Grounded theory approach
Shim et al. 2012, U.S.	21 spouse caregivers aged 47–91 years	Series of interviews	Manifest and latent content analysis
Shim et al. 2013, U.S.	11 family caregivers aged 63–81 years	Semi-structured interviews	Thematic qualitative content analysis
Steeaman et al. 2006, Belgium and Netherlands	Systematic review of qualitative studies	Databases: MEDLINE, CINAHL, and PsychINFO, in addition manually selected studies.	Meta-synthesis
Steeaman et al. 2007, Belgium and Netherlands	20 patients aged 69–91 and their close relatives	Individual and joint in-depth interviews	Grounded theory approach
Steeaman et al. 2013, Belgium	17 patients aged 72–91 years and their close relatives	Individual and joint open interviews	Grounded theory approach
Stokes et al. 2014, UK	10 spouse caregivers	Semi-structured interviews	Interpretative phenomenological analysis
Stone & Jones 2009, U.S.	33 adult children aged 36–67 years	Semi-structured interviews	Grounded theory approach
Svanberg et al. 2010, UK	12 children of persons with early onset memory disorder aged 11–18 years	In-depth interviews and quantitative questionnaires to assess burden, distress and resilience	Grounded theory approach and quantitative analysis
Svanberg et al. 2011, UK	Systematic review	Databases: PsychINFO and MEDLINE, in addition manually selected studies	Narrative synthesis
Svanström & Dahlberg 2004, Sweden	Five patients aged 73–80 years and their spouses aged 72–79 years	Unstructured individual interviews	Phenomenological approach

Author(s), year and country	Study participants / material	Data collection method	Data analysis method
Sørensen et al. 2008b, Denmark	11 patients with Alzheimer's disease aged 65–82 years	Semi-structured in-depth interviews	Grounded theory approach
Taşcı et al. 2012, Turkey	Eight family caregivers (mean age 49 years)	Focus group interviews and questionnaire	Thematic analysis
Vaingankar et al. 2013, Singapore	63 family caregivers (mean age 63 years)	Focus groups and semi-structured interviews	Thematic analysis
Van Vliet et al. 2010, Netherlands	Systematic review	Databases: PubMed, PsychINFO and CINAHL	Assessing the quality of the studies and analysing quantitative and qualitative outcomes
Vellone et al. 2012, Italia and U.S.	41 informal caregivers aged 26–78 years	Interviews	Phenomenological approach
Vernooij-Dassen et al. 2006, Netherlands and UK	18 couples with patients and their spouse caregivers	Semi-structured individual interviews	Grounded theory approach
Vikström et al. 2008, Sweden	26 couples with patients aged 62–85 years, and their spouse caregivers aged 59–86 years	Semi-structured individual interviews	Grounded theory approach
Virkola 2014, Finland	Five women with memory disorder aged 71–90 years	Ethnographic discussions and observations	Inductive and deductive data analysis, narrative and discourse analysis
von Kutzleben et al. 2013, Germany	Systematic literature review	Databases: PubMed, PsychINFO, Cinahl, EMBASE, Gerolit, Cochrane Library in addition Google Scholar	Thematic analysis
Vreugdenhil 2014, Australia	Case study of four adult child caregivers	In-depth interviews	Case study methodology

Author(s), year and country	Study participants / material	Data collection method	Data analysis method
Välimäki et al. 2009, Finland	170 spouse caregivers aged 48–85 years	Several assessment batteries (BDI, SOC- Scale, 15D-questionnaire, VAS, GHQ.) to evaluate caregivers' depression, sense of coherence, health related quality of life and distress. In addition patients' cognitive functioning, severity of the disease and activities of daily living were assessed using questionnaires (MMSE, CDR, NPI and ADCS-ADL).	Statistical analysis using SPSS
Välimäki et al. 2012, Finland	83 family caregivers aged 41–85 years	Unstructured diaries	Qualitative content analysis
Ward-Griffin et al. 2006, Canada	10 mothers with memory disorder aged 75–98 years and 15 caregiving daughters aged 35– 63 years	Semi-structured individual interviews	Qualitative data analysis
Werezak & Steward 2002, Canada	Six patients aged 61–79 years	Semi-structured interviews	Grounded theory approach
Werner et al. 2010, Israel	10 adult children aged 42–67 years	Semi-structured in-depth interviews	Qualitative content analysis
Williams et al. 2014, UK	Close relatives of persons with memory disorder (n=8) and stroke (n=5) aged 33–73 years	Semi-structured interviews and use of photographs	Interpretative phenomenological analysis
Wolverson et al. 2010, UK	10 patients aged 72–87 years	Semi-structured interviews	Interpretative phenomenological analysis

Author(s), year and country	Study participants / material	Data collection method	Data analysis method
Zuccella et al. 2012, Italy	126 pairs with patients aged 59–89 years and their family caregivers (mean age 56 years)	Several assessment batteries (CBI, COPE-Scale, MMSE and NPI) to evaluate caregivers' burden, distress and coping strategies, and patients' cognitive functioning and behavioural disturbances.	Statistical analysis using SPSS

## Appendix 2 Ethical and methodological issues found during the data collection

Target of analysis	Situational factors	Ethical concerns	Methodological solutions
Considering the altering situation of the person with a memory disorder and the family caregiver	The transitional process and the challenging life situation of the study participants due to a recently diagnosed progressive memory disorder.	How to minimize the distress and burden of the study participants	<p>Having the interviews in the homes of study participants to make them feel comfortable and safe.</p> <p>Being prepared to make compromises during individual and joint interviews.</p> <p>Aiming to create a positive atmosphere before and after an interview with small talk.</p> <p>Aiming to create an approving atmosphere by respecting study participants' experiences, having an unprejudiced attitude, and being personally present.</p> <p>Paying attention to the duration of the interviews and including pauses as needed.</p> <p>Observing the well-being and resources of all study participants.</p> <p>Paying attention to supportive aspects, such as strengths, capabilities, and possibilities in life.</p> <p>Avoiding stereotyped and stigmatized expressions.</p> <p>Ending each interview with a positive atmosphere.</p>

Target of analysis	Situational factors	Ethical concerns	Methodological solutions
	Interviews conducted mainly as joint interviews according to study participants' choices.	How to enable the participants' voice to be heard equally during joint interviews	Observing the communication and interaction between study participants. Listening attentively to both study participants' experiences. Encouraging all individuals to express their own viewpoints. Promoting interaction between study participants by asking another study participant's for opinion / experiences with issue being discussed.
	Cognitive symptoms of the person with a progressive memory disorder.	How to provide the participants' voices to be heard despite cognitive problems and difficulties with verbal expression	Directing the interview tactfully as necessary. Valuing both perspectives and not taking sides. Allowing time and space in interviews and tolerating silence. Using concrete words, repeating questions differently when needed, and listening attentively. Asking for experiences, not strict details.

Target of analysis	Situational factors	Ethical concerns	Methodological solutions
The role of the researcher	The researcher's role as a nurse researcher and any possible role conflicts.	How to clarify the researcher's role and deal with the nurse researcher's role conflict	<p>Preparing beforehand for research interviews with vulnerable people and possible role conflict as a nurse researcher by reviewing the methodological literature.</p> <p>Foreseeing possible ethical dilemmas before entering the field.</p> <p>Preparing before each interview for the possible need of further support of study participants and the services available.</p> <p>Aiming consciously to implement a responsible practice.</p> <p>Clarifying the researcher's role to oneself.</p> <p>Explaining the researcher's role to all study participants.</p>
	Conducting research interviews with vulnerable people.	How to deal with the possible emotional burden of the researcher	<p>Dealing with emotional burden by reflecting experiences and emotions in a research diary.</p> <p>Aiming to carry out and develop situational sensitivity by reflecting on research interviews afterwards.</p> <p>Utilizing sufficient supervision and discussing any methodological and ethical questions with supervisors.</p>

## Appendix 3 Examples of subcategory citations for the category ‘Phases of the families’ illness trajectory’

Subcategories for the category ‘Phases of the families’ illness trajectory’	Examples of citations
Recognizing the symptoms	<p>PMD1: Well yes... We noted that one reason for the problems had to be burnout.</p> <p>FC1: And also depression.</p> <p>PMD1: Yes, that’s true. Depression was one thing</p> <p>FC1: Yes, the one thing that we assumed to be the reason.</p> <p>PMD1: Yes.</p> <p>FC1: So it was this burnout at work and problems with her back and all these combined, so we assumed that depression explained all this at first.</p> <p>PMD1: Yes, that’s how we thought.</p> <p>FC8: I thought that maybe it is because of his age, but then on the other hand not, not because of the age, so there has to be something else. But I didn’t think that it could be dementia. He couldn’t remember things and started to argue against everything. And because he couldn’t remember, then I was the bad person, as he was always right. We had arguments, I meant another thing, and he meant another. I used to say that we are both right, we just talked different issues. Now that I’ve read these guidebooks, I feel like Oh my God, those symptoms were just like those in our family.</p> <p>PMD8: At the beginning I didn’t think that that the reason could be memory problems. Somehow it just started to feel that things are not going in a right way, as they should go. Then it took months, several months, and I think that then things started to get worse, not too bad but anyway. Then months passed by, but we managed... Eventually I had to...</p> <p>FC8: ... admit, yes, I said that listen to me, if this is something serious, it will get worse if we won’t do anything. Our</p>



daughters wouldn't believe all this. They said that Mother is making a fuss over this, and men can be so absent-minded. I said to them that "Listen now, it's really difficult to tell the difference between what normal forgetfulness is and what is not and where the line goes".

Seeking professional help

- PMD4: I couldn't use the farming machinery like I used to do. Almost all my work came to an end. I didn't dare to drive those machines anymore. All went wrong, and I knew something must be wrong with me.
- FC4: I remember that one critical episode was with the chainsaw, when you couldn't change the chain.
- PMD4: I really tried to do it. It took me almost a whole day, but I couldn't do it.
- FC4: And I couldn't believe that you didn't manage to do it. That was the final straw. All your life you have used the chainsaw, and now you couldn't. I thought this can't be true, and I phoned the health center. It was so difficult for you to go to see the doctor and have an examination, because you don't want to give up.
- PMD4: Yes, that's true.

FC5: Well, I'd say that about a year ago we already noticed and tried to take Mother to the doctor, but she wouldn't go. Last autumn everything started to go wrong ... for example, Mother didn't know which bus to take when she left work.

PMD5: I didn't want to go, that's true. Since then my daughter has taken care of these doctor-things, which is really good.

Diagnosis as a mutual turning point

- PMD1: Well, at first, it felt really shocking, terrible, but well ... you just have to adjust to this. There's no escape from this.
- FC1: Yes, but on the other hand, when the reason was found, I mean certainty of the reason, then this exhausting uncertainty ... well, in that respect it was a relief. But you worried quite a lot about how I'll manage with you; you've asked many times if I have strength to be with you and how I feel. But we haven't given up. We are going to counter-

attack with every which way we have.

PMD1: Yes, and I think it's a resource that we can speak openly about this.

PWD3: It was through occupational health care... and memory clinic. I got the diagnosis of Alzheimer's disease. I think it's an older persons' disease, I wonder how can I have it.

FC3: Well, I've adjusted to it. There's nothing much you can do about it. I don't know if I'm too calm. There's no point in worrying, as it doesn't change anything.

PMD3: I think our life hasn't changed much.

FC3: I agree. I've already stayed at home [as unemployed] for two years now.

PMD3: I think it may be that I can't continue working anymore. I'm on sick leave now. Actually I feel relieved by it... that apparently I don't have to go to work anymore. I felt that I wasn't accepted in the work community anymore. Still, it was kind of a shock, the diagnosis I mean.

FC3: Sometimes I wondered why she was waiting so many hours just to get to work, but it's not easy to know... However I didn't expect this serious illness.

PMD5: I didn't believe that I'd have something wrong with my head. I thought that it's just exhaustion. It saddens me that I have this disease. I wouldn't have thought so. It all happened so quickly.

FM5: I think it's good that we know what the matter with Mother is because this has lasted for over a year now. It's good that it has a name. We can go forward one day at a time, and we've managed quite well so far.

Seeking a new equilibrium

FM2: We moved here [sheltered accommodation] about a month ago.

PMD2: So we haven't started to feel at home yet.

FM2: The reason we moved here was her memory problems. Of course part of the reason was that we had a large plot. Winter is coming, and snow clearing is quite hard for me as also my own health is not as before.

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Subcategories for the category 'Phases of the families' illness trajectory'      Examples of citations

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PMD2: And I'd become a bit bored cleaning our home. It's because we don't need that much space anymore. But anyway we don't want to give our home away. We built it ourselves and lived there for so long.

PMD3: I've tried to exercise outdoors more, when the weather permits... When I was working, it didn't work out but now I've tried to go outdoors every day. And we've planned that we'll get an exercise bike because in winter, when it's cold, you can't go out.

FM3: Yes, the idea is that we should exercise more, just to have something to do.

PMD7: Because the medication is available. I'm not so terrified about this. I can manage with my ordinary duties.

FC7: Although somehow the diagnosis faded and stopped. But then we just thought that we have to live with this and see how we'll manage... When he was diagnosed, and I was still working, I worried because he had to stay at home during the whole day, and I tired myself out. My heart was beating every time I went home, as I was afraid that something had happened. Then one day I went to see the doctor and he signed me off for 3 months. He noticed that I was really exhausted. Later I had to lengthen my sick leave since I couldn't concentrate on anything and I really needed to struggle to manage at work, I lost weight and there were days when I couldn't eat anything. But now I feel quite contented with our situation and that we have turned a corner. I've returned back to work, and now I work a shorter time, so my worrying about how he's getting along at home has relieved. And the rehabilitation course we attended was just perfectly timely. We got useful information and met others in the same situation.

PMD7: And we haven't curled up on the couch. Our cottage has been our way to relax, even when we both were on a sick leave.

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## Appendix 4 Examples of subcategory citations for the category 'Restructure of roles and identity'

Subcategories for the category 'Restructure of roles and identity'	Examples of citations
Adjusting to altering self	<p>PMD1: At first, I rejected it, but now ... I've accepted my disease. I know that I can get all the help that's available. And it's good that I've got a diagnosis, even though it's terrible. I feel the outrage and rejection, and my worst fears, but somehow... I've accepted all this, at least in some way. I've adjusted, I could say. I feel that I've become more open to receive help. I'm not that self-confident and self-satisfied and perfectly accomplished as I used to be. It's nice to receive help and care and services and all that. From my point of view that's a positive change.</p>
	<p>PWD2: I use to be very good-natured and happy person, but I've noticed that nowadays I've become quite nasty. Well, it's all because of my head. Anyway it's from the head that a worm dies. Brains are a really important part of a body. I'm not sure if I can even laugh anymore. These hard times have affected me, even if I've tried to take another kind of attitude. Maybe I've been captured by my troubles, I don't know. I have to admit that I've become quite lazy. I used to be a hard-working person, but it's all changed. I'm no longer interested in doing anything.</p>
	<p>PMD4: When you have it, you have it. There's nothing you can do about it. I'm living my life little by little. My life goes as it goes, and eventually it comes to an end.</p>
	<p>PMD7: I'm not grieving my situation. It's good the doctor has explained openly what this is all about. The doctors have asked me if I'm worried. I've said that I feel comfortable with myself and my disease. I know what I have; the doctor explained it to me, so I'm not worried.</p>

Subcategories for the category 'Restructure of roles and identity'	Examples of citations
Adapting to a new caregiver role	<p>FC1: Now when we've faced these problems, I must say that you've opened up more, and somehow I feel that you've turned to me, almost seized on me, but not in a negative way. Before you had this attitude that you'll manage on your own, and sometimes it has been somewhat agonizing. We could manage together, and it could be easier that way. I've found it satisfying that I have a so-called utility value to you. I've been thinking what the sorrow is that she's keeping inside when she's isolating herself. What could I do? Should I keep the distance or push her into activities. I really have a will to help her.</p> <p>FC2: I'm responsible for all our household work now. I'll do everything according to my resources. It's just that she [wife] won't accept me as her caregiver...All this requires understanding. Sometimes she gets cranky because of her memory problems...I do understand that she has this disease, but it's not always easy to remember that.</p> <p>FC4: Of course, this disease appears in everyday life; you can't deny that. But we've learned to live with it. There's no reason to stop living, and to worry about this. Sure it's sad that this had to come to our family, but we try to talk things over. After all, we've lived two years with this. I've also had some difficult times and deal with my emotions. You can't get along if you store everything inside. It becomes too distressing.</p> <p>FC7: Many times, I've thought how nice it would be to stay home with you. On the other hand, many have said to me that it's good I have a job. Anyway, I've managed to stop the terrible worrying while I'm at work. I've noticed that you're getting along just fine at home. It was a huge change, since at first I was on sick leave, and later I was able to work again. My thoughts have cleared, and I feel we can live with this. You're able to stay at home during the day. Sometimes my colleagues at work ask how he's managing at home, and I say he's doing all right.</p>

## Appendix 5 Examples of subcategory citations for the category ‘Mutual processes for managing life with a memory disorder’

Subcategories for the category ‘Mutual processes for managing life with a memory disorder’	Examples of citations
Acknowledging available qualities and resources	<p>PMD1: Somehow I push myself so much, and when I feel that I don't have strength to do things, I get depressed. I think nobody wants to admit weaknesses. As a mother and a working person, I've expected a lot of myself, and of course when I was younger, I was able to manage my duties. Now it's hard for me to accept myself as am incapable, lazy, and sick person.</p> <p>FC1: You value yourself by your achievements, that's true. But you still achieve a lot. However, what I'd like to emphasize in our life is that our circle of life wouldn't become narrower, and that you could be more active, and we would have more contacts with others. We both have a feeling that our circle of life has become narrower. If we would be more active, we'd get more energy and joy in life. You've said I should kick you on the move. Though it's hard to know how hard I can kick you [laugh].</p> <p>PMD1: I think I've said to you how nice it has been when you've dragged me, that it was good that we've made a move.</p> <p>FC4: I think our situation is quite good. I can't say that your condition has worsened.</p> <p>PMD4: No, it hasn't.</p> <p>FC4: This is the second year, and I think your functioning is like before.</p> <p>PMD4: Yeah, it is just like before.</p> <p>FC4: You walk quite a lot, also alone. There are no problems with that. You also ride a bicycle.</p> <p>PMD4: I walk with our dog, often ... and also alone.</p>

Subcategories for the category 'Mutual processes for managing life with a memory disorder'	Examples of citations
	<p>FC4: Yes, the dog is so important. I think moving here [new apartment] was a good thing. We couldn't have managed in our farm anymore. It required so much effort. I couldn't have managed alone, so it was good that our son started to work there instead. Now we can visit there when we want and help him. Last spring we were working in the fields, and you harrowed 5 hectares on one day. And really, he sowed the field with barley. Although at the memory clinic, they told us that he should never use the machinery.</p> <p>PMD4: That I shouldn't go even near the machinery.</p> <p>FC4: But I haven't forbidden it/ Why should I, at least as long as it works out? We've been a great help to our son. And I think it would have been terrible if I would have said don't touch anything, don't do anything. It would have been a real collapse for you. I don't think this situation is a problem for us. I take care of the medication. Sometimes you forget what day it is, and then we repeat it. The doctor said that I'm denying his disease, but I'm not.</p> <p>PMD4: That's true. Where it would have disappeared.</p> <p>FC4: I explained to the doctor that we try to live a normal life. We haven't resigned ourselves. We'll go as long as we can. It's the most important thing. And we have wonderful neighbors. You've told them that you have memory disease, and sometimes you forget words. You wanted to say it yourself. It's okay. I think it's good. Why should you hide it?</p> <p>PMD4: Because you have, you have it. There's nothing you can do about it.</p> <p>FC4: We live with it, one day at a time and see what tomorrow brings along. Nobody knows tomorrow. Some days can be good, and some worse. When I notice that you're feeling bad I encourage you on the move. Stimuli are really important.</p>

Subcategories for the category 'Mutual processes for managing life with a memory disorder'	Examples of citations
	<p>PMD5: I've noticed that I'm not interested in cooking or baking anymore. First of all, I don't know how to put on the oven. I can turn it really hot and keep the food there too long. So it won't work at all.</p> <p>FC5: I think it's good that you've noticed it yourself and decided not to use it anymore.</p> <p>PMD5: That's why I've decided not to use the oven at all. I even don't use the microwave oven or washing machine or anything anymore. All I do is wash myself, eat ready-to-eat food, and know how to vacuum-clean.</p> <p>FC5: You can always bake here with my sons. As a matter of fact, you can start baking for Christmas [laugh].</p> <p>PMD5: And then I can't go cycling far away anymore.</p> <p>FC5: There's a risk of getting lost.</p> <p>PMD5: Yes, that I don't know how to return. Quite often it has happened that even though the environment is familiar, I suddenly don't remember where I should go. I remember once I got so nervous, and after that, I haven't had the courage to go really far. I think I needed to ask someone where I was.</p> <p>FC5: It's true you've had to ask how to get back to home.</p> <p>PMD5: After that, I haven't dared to go anywhere alone.</p> <p>FC5: Or at least nowhere further or an unfamiliar place.</p>
Seeking meaningful social support	<p>FM3: It seems that she [the wife] bottles up all this. Our relatives don't know about her disease. She really can't open her mind. She's mourning alone. And we don't talk about her disease with each other. Only close relatives [children and wife's siblings] know. We haven't told anyone else. Who knows what they are thinking, but we haven't told them. I've thought that if she doesn't want to tell, then we don't. --- We had a chance to attend a rehabilitation course and it was also important for me as a family caregiver. I've also attended a course once a month while she joins a physical exercise group. Although the other family caregivers are older than me, I still get on quite well there.</p>



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Subcategories for the category 'Mutual processes for managing life with a memory disorder'

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Examples of citations

PMD6: I have lot of important things in my life, things that give me reason to live. Our grandchildren need me. And I think I'm important for my husband too. It may be that you are even more important in sickness. We've always rowed this boat together. I'm so happy that we still care and love each other and show it. Our good marriage is a great resource. I don't think he would loosen his hand from my hand, even though I'm diseased. I feel I don't need the company of those who are at the same situation as me. I don't think that it would help me if I spend time with others who have this same disease. But now, before I forget, there's something important I'd like to talk about. I understand that also he [husband] has a hard time. So, we should ask how he's doing.

FC6: Well, we don't have a real problem here. It's just that it's become more difficult for me to leave home. I can't think about going, for example, to play volleyball or something. But of course I can exercise at home, I have weights here. --- But I have to say that it was good and interesting that course we took part in. I noticed that there are others who have the same kind of problems.

FC7: What I need is more peer support. That course that we took after the diagnosis was really wonderful! I would like to hear how those people are doing now. It would be really wonderful.

PMD7: I'm not interested. When my memory starts to worsen more, then I may consider it. I don't think it's realistic for me to participate. I've been in a conversation group, and it wasn't useful. The Memory Park is mostly conversational. And if they give lectures, it's all familiar to me. And besides, I think the people there are older than me.

FC8: Well, we actually didn't get any proper advice last time [from the memory clinic]. They just increased the medication. I feel I have to deal with all this by myself. It's quite burdensome for me. And one thing that's quite

Subcategories for the category 'Mutual processes for managing life with a memory disorder'

Examples of citations

surprising is the reaction of our children. I think they don't believe me or won't accept that we have troubles and that their father needs assistance. We haven't succeeded in talking about things openly. --- What I need is just to chat and exchange experiences. I don't need anything special. I've been talking with our neighbors.

Living for today

PMD2: Well, we have to live through these troubles, and eventually we just pop off.

FM2: Yes, each one of us has our time. There's no point for you to trouble yourself.

PMD2: Well no, but eventually we just pop off.

FM2: Yes we do, every one of us, when the last night train comes.

PMD2: And for me the time is near.

FM2: You can't tell that. But I still think that the future looks quite bright, if we just stay healthy. At least as long as I'll be able to take care of things. We won't surrender yet. Somehow I can still manage. We'll live one day at a time. And we have no problems. Only that as I'm acting as a paid family caregiver, I should have 2 days off per month.

PMD2: Yes, but then you should cart me off somewhere.

FC2: Yes I should. And I don't have a heart to do that.

PMD2: Oh please, come on [laugh]. Don't talk superlatives. You'll become responsible for that.

FM2: You are such a good patient [laugh].

FC3: Well, the situation has worsened. But we have to take one day at a time. It's only two years back when she stayed on a sick leave. There's no point in grieving beforehand, on the contrary.

PMD3: I only hope we can manage with this.

Subcategories for the category 'Mutual processes for managing life with a memory disorder'	Examples of citations
	<p>FC3: Well, the situation has worsened. But we have to take one day at a time. it's only two years back when she stayed on a sick leave. There's no point in grieving beforehand, on the contrary.</p>
	<p>PMD3: I only hope we can manage with this.</p>
	<p>FC7: I see it in a way that we'll live one day at a time. I have to be realistic about what the future brings along.</p>
	<p>Only thing that I'm worried about is your physical functioning. I wish it could maintain. You're such a big man, if you'll become incapable of moving, how I can manage with you.</p>
	<p>PMD7: Well, I've planned that I need to be in good shape, exercise, and so on. That's important. Then I need to eat proper, healthy food. Sometimes I have a desire for something, like smoked herring. When I gave up my driver's license, I decided that we'll take care of things together, go shopping to the marketplace and market hall.</p>
	<p>That's what I used to do when I was still working. I want to live a normal life.</p>



## Original publications

- I Pesonen HM, Remes AM, Isola A (2011) Ethical aspects of researching subjective experiences in early-stage dementia. *Nursing Ethics* 18(5): 651–661.
- II Pesonen HM, Remes AM, Isola A (2013) Diagnosis of dementia as a turning point among Finnish families: A qualitative study. *Nursing and Health Sciences* 15(4): 489–496.
- III Pesonen HM, Remes AM, Isola A (2014) Managing life-altering situations: A qualitative longitudinal study of the experiences of people with memory disorders and their family caregivers. *Journal of Nursing Education and Practice* 4(10): 60–73.

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Original publications are not included in the electronic version of the dissertation.



1275. Harjunen, Vanessa (2014) Skin stem cells and tumor growth : functions of collagen XVIII in hair follicle cycling and skin cancer, and Bmx tyrosine kinase in tumor angiogenesis
1276. Savela, Salla (2014) Physical activity in midlife and health-related quality of life, frailty, telomere length and mortality in old age
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